

Women's Experience of Maternal Mental Illness, Stigma, and  
Accessing Mental Health Care

A Thesis Submitted to the  
College of Graduate Studies and Research  
In Partial Fulfillment of the Requirements  
For the Degree of Master of Education  
In the Department of Educational Psychology  
And Special Education

University of Saskatchewan  
Saskatoon, Saskatchewan  
Canada

By  
Jocelyne F. Leham  
January 2015

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## **ABSTRACT**

In recent years, mental illness in pregnant and postpartum women has become a public health concern. Untreated and undertreated maternal mental illness has a significant negative impact on not only the mother, but also on the baby and family. Further, many women do not seek help or access mental health care due to stigma surrounding mental illness, the unrealistic social expectations of motherhood, and the fear of being judged or rejected. An interpretive descriptive study informed by a feminist perspective was conducted with six postpartum women who sought maternal mental health care services. Semi-structured interviews provided an opportunity to explore women's experiences of having a maternal mental illness, accessing care, and the role of stigma. Analysis focused on the bio-psycho-social dimensions of their experiences. A shared experience and meaning emerged: self stigma and expectations of motherhood, stigma and infertility, factors influencing self stigma, level of self-efficacy, and treatment satisfaction, engagement and outcome. Findings are discussed with reference to the current literature on maternal mental illness, stigma, and infertility. Findings are conceptualized using Brown's (2006) Shame Resilience Theory, implications for practice are presented including women's advice to other women, and recommendations for future research are made.

## ACKNOWLEDGMENTS

I would like to acknowledge the six mothers who had the courage to share their experience of maternal mental illness and the stigma.

I would like to extend sincere thanks to my thesis committee for their time and patience throughout this process. Your flexibility and understanding allowed me to have the gift of time to spend with my loved one during the last few months of her life. For that I will always be grateful.

Thank you to my thesis co-supervisor Dr. Jennifer Nicol for your support, patience, feedback and guidance during the course of this project.

Thank you to Dr. Angela Bowen my other thesis co-supervisor for the opportunity to conduct this qualitative research project with the funding provided by Saskatchewan Health Research Foundation.

To Dr. Stephanie Martin, I appreciate your feedback and support, as well as your knowledge and enthusiasm for women's mental health using a feminist lens.

I would also like to thank Dr. Pamela Downe, my external examiner, for your knowledge, expertise and support.

I began this journey so many years ago in Women & Gender Studies classes, which ignited my passion for women's mental health and wellness. Being a feminist has influenced my epistemology, methodology, worldview, praxis and psycho-therapeutic approach, and my way of being-in-the-world. I feel like I have come full circle, a fitting conclusion to this very long adventure.

## **DEDICATION**

This thesis is dedicated to the men in my life- to my husband Peter, and to our four sons, Tarek, Caleb, Brydon, and Rhys. We started this journey as a family so many years ago; the struggle and sacrifice has forged and strengthened our family bonds.

Thank-you Peter for all that you are; for your love, support, encouragement, patience, and your loving care and attention to me and the boys; for your belief and confidence in me; for taking on the load of everything when all I could focus on was this arduous journey; for being my rock and my still-point in the midst of the pain and chaos of loss. You have always encouraged me to spread my wings and fly; you are the wind beneath my wings; it is because of you that this was all possible. You make me a better woman, wife and mother; I love you with all my heart and soul. I can't wait for this next phase in our life together- the unfolding of our hopes and dreams.

Thank-you to my boys; for your love, support, laughter and togetherness. When we began this adventure, you were boys and through this difficult process you become amazing, caring, and sensitive men. I am so proud of you; you have enriched my life, I love you all so much.

To the women in my life- my mother, Jeannine Fournier Lizee, my step-mother, Martha Watteyne Lizee, my memere, Anna Lizee, and my great aunts, Sr. Marie-Alice Lizee, Sr. Laurianne Lizee, Sr. Simone Lizee, and Sr. Marie-Ephrem Lizee; although you did not know it you were my first feminist role models, guides, and elders. Thank-you for your strength, courage, independence, and fortitude; you are forever in my heart.

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## **CHAPTER 1: INTRODUCTION**

I came to this project when I applied for a funded position (Saskatchewan Health Research Foundation) as a graduate student to conduct a qualitative inquiry of maternal mental health as a Master's thesis. My interest in researching women's mental health issues began with my first introduction to women and gender studies; hence, this position provided the opportunity to continue my interest and research in this area. Due to my personal experience with maternal mental illness, this project was particularly meaningful for me, especially in view of meeting the needs of pregnant and postpartum women struggling with mental illness in my community. However, it was not until I read the scientific research for this study that I pondered the impact of having increasingly severe antenatal anxiety and depression during and after each of my four pregnancies, on myself, my children and my family. Consequently, I believe in the importance and the value of having health care that targets and supports the needs of women with maternal mental health problems by providing better access to mental health care services and promoting educational opportunities for health care providers. I also recognize the limitations of a biomedical model and the importance of identifying and addressing psycho-social factors and issues of stigmatization when helping women with mental health problems, and including their families when providing mental health care services, information/education, and support.

### **Maternal Mental Health**

In recent years, mental illness in pregnant and postpartum women has become a public health concern. Mental health problems, such as anxiety and depression, are twice as likely to affect women than men (Parikh, Lam, & CANMAT Depression Work Group, 2006). Depression is one of the greatest causes of worldwide maternal mental illness in women of childbearing age

- approximately 15 to 44 years- and the “contribution to the Global Burden of Disease (GBD) is 7% of the total (GBD) for women of all ages” (World Health Organization, 2008). Postpartum depression (PPD) occurring within the first year after delivery, affects 10% to 25% of women globally (Brockington, 2004; Gold, 2002; Marcus, 2009; McCarthy & McMahon, 2008).

Although PPD is most often associated with maternal mental illness, other indications of mental illness are important to consider. Prevalence rates for antepartum depression (during pregnancy) in different populations of women, range from 4 to 57% (Bennett, Einarson, Taddio, Koren, & Einarson, 2004; Bowen, Bowen, Butt, Rahman, & Muhajarine, 2012; Marcus, 2009). Further, depression and anxiety, during and after pregnancy, have been found to occur simultaneously (up to 33%) in mothers with mental illness (Austin et al., 2010; Britton, 2005). Hence, the importance of considering not only depressive symptoms, but also anxiety symptoms when pregnant and postpartum women seek help from their health care providers. Moreover, pre-existing mental illness increases the risk of developing maternal mental illness during and/or after pregnancy (Austin, Tully, & Parker, 2007; Bandelow et al., 2006; Gold, 2002).

Research indicates that women with prolonged and/or undertreated maternal mental illness are: at an increased risk of complications during pregnancy; more likely to have adverse neonatal outcomes; less likely to breastfeed; may have problems with infant-mother attachment; at risk for chronicity and severity of maternal mental illness; and more likely to have problems with self care, sleep, and substance abuse (Bonari et al., 2004; Bowen et al., 2012; Da Costa et al., 2010; Marcus, 2009; Seto, Cornelius, Goldschmidt, Morimoto, & Day, 2005). In addition, there is an increased likelihood for children of anxious and depressed mothers to have psychopathology, developmental problems, difficulty with feeding and sleeping, and they may have more emotional and behavioural problems than children of non-depressed mothers

(Bellingham-Young & Adamson-Macedo, 2003; Marcus, 2009; Talge, Neal, & Glover, 2007).

Hence, there is a growing need for ensuring optimal mental health for women during their reproductive years by providing adequate maternal mental health care to enhance the well-being of mothers and their families, which would further facilitate healthy child development (Muhajarine, 1999).

Prolonged or undertreated maternal mental illness has deleterious effects not only on the mother and baby, but also on the spouse placing undue strain on relationships and family functioning. For instance, depression ranged from 24% to 50% among men whose spouse had PPD (Goodman, 2004). Indeed, the lack of detection and treatment of maternal mental illness has devastating and long-lasting ramifications for the mother, the baby and the family unit, and the community-at-large.

Although research indicates the frequency and potential negative effects of maternal mental health are an increasing concern, symptoms of depression and anxiety in pregnant and postpartum women are often overlooked by women and their primary care providers (Cohen & Nonacs, 2005; Gold, 2002; Marcus, 2009). There is controversy surrounding the use of psychotropic medication in pregnant and postpartum women, despite readily available evidence-based information regarding the efficacy and safety of certain medications (Einarson, 2009a; Wisner, Applebaum, Uhl, & Goldkind, 2009). Further, when health care providers use psychotropic medication to treat women with mental illness, they are more likely to be overly cautious and to undertreat pregnant women (Einarson, 2009b; Yonkers et al., 2009).

The treatment of maternal mental illness has been predominately based on a biomedical model that focuses on psycho-pharmaceutical interventions. According to Tufano (2000), the biomedical model concerns itself with:

...the disease processes and pathology associated with disorders or illness. The focus of the biomedical model is to alleviate symptoms and find cures based on scientific evidence from research. Treatment is given in a medically prescriptive manner and designed to improve the malfunctioning physical component of disease and disorders. The biomedical model provides an objective and structured way to deliver health care, a necessary and effective mission. Therefore, with the context of its very definition and core, the biomedical model focuses on the physical entities of disability rather than the psychosocial impact of a disability (p. 113).

Research indicates that pregnant and postpartum women with mental health problems often receive inadequate mental health care, and/or do not seek help due to: a lack of personal insight and awareness of symptoms; stigma and a fear of being judged; a lack of knowledge of PPD; denying and minimizing their symptoms; a lack of and/or limited access to mental health care services; and under-diagnosis by health care providers who may minimize or discount women's symptoms of emotional distress (Dennis & Chung-Lee, 2006; Marcus, 2009; Pinto-Foltz & Logsdon, 2008). Consequently, several qualitative researchers have suggested the importance of exploring women's subjective experiences of living with maternal mental illness and identifying various help-seeking barriers/facilitators experienced by pregnant and postpartum women. This approach would expand existing knowledge beyond the biomedical model and enhance a deeper understanding of women's experiences of maternal mental illness and its psycho-social dimensions so that health care professionals can provide effective treatment and support (Dennis & Chung-Lee, 2006; McCarthy & McMahon, 2008; Pinto-Foltz & Logsdon, 2008; Wardrop & Popadiuk, 2013). Therefore, the primary goal of this study was to explore

women's lived experience of maternal mental illness and accessing care within their socio-cultural context.

One of the greatest barriers to seeking care for and managing maternal mental illness is the stigma surrounding it (Ahmed, Stewart, Teng, Wahoush, & Gagnon, 2008; Corrigan & Wassell, 2008; Dennis & Chung-Lee, 2006; Halter, 2004; Kenny, 2001; Tognazzini, Davis, Kean, Osbourne, & Wong, 2008). Stigma is a social construction which has various nuances and is experienced within a socio-cultural milieu. The *social stigma* associated with mental illness represents socially-held and collectively-agreed-upon values, beliefs, and misconceptions which serve to characterize, categorize, and label individuals with mental illness (Corrigan & Wassell, 2008, p.43). When people agree and apply social misconceptions to individuals with mental illness, these stereotypes often lead to prejudice and discrimination, which is referred to as *enacted stigma* (Corrigan & Wassell, 2008; Green, Hayes, Dickinson, Whittaker, & Gilheany, 2003). *Self stigma* occurs when an individual identifies and internalizes the negative stereotypes of mental illness which may result in self-devaluation and a struggle with positive self-esteem and a lack of self-efficacy (Corrigan, Larson, & Rusch, 2009). Consequently, people may avoid seeking help and accessing mental health care because of the fear of being labeled with a mental illness and the fear of being judged, rejected or seen as less than, which is referred to as *perceived stigma* (Corrigan et al., 2009; Green et al., 2003). The experiences and implications of social and self stigma are multi-faceted and complex, especially for women struggling with maternal mental health concerns.

The stigma associated with maternal mental illness is inextricably linked to the socio-cultural context within which a woman finds herself and which serves to define what it means to be a woman and a mother (Arendell, 2000; Choi, Henshaw, Baker, & Tree, 2005; Koniak-

Griffin, Logsdon, Hines-Martin, & Turner, 2006). For feminist researchers and scholars, women's lives and experiences are embedded in society's notion of motherhood which is considered compulsory, natural, and normal for all women and in society's unrealistic expectations of joyful mothering as easy, wonderful, ultimately fulfilling and the peak of a woman's achievement (Koniak-Griffin et al., 2006; Woollett & Boyle, 2000). These socio-cultural standards then become the measuring stick by which a mother gauges her own experience. Pregnant and postpartum women struggling with mental illness may internalize a sense of being a bad and/or unfit mother, or being perceived as being a less-than-perfect mother which often results in a fear of disclosure (Dennis & Chung-Lee, 2006; McCarthy & McMahon, 2008; Pinto-Foltz & Logsdon, 2008). Researchers found that pregnant and postpartum women under-reported distressing symptoms because they feared having their children apprehended if they revealed the level of emotional and mental distress and feared being labelled unfit if they admitted being unable to manage their symptoms and cope with the demands of mothering (Dennis & Chung-Lee, 2006; McCarthy & McMahon, 2008; Pinto-Foltz & Logsdon, 2008). Further, women have reported experiences of stigmatization in their interactions with health care providers, and/or their perception of dismissive attitudes, as another major deterrent in seeking help and accessing mental health care (Ahmed et al., 2008; Dennis & Chung-Lee, 2006; Pinto-Foltz & Logsdon, 2008).

Qualitative health researchers endorse further exploration of women's subjective experience of stigma to increase awareness, understanding and sensitivity surrounding the negative impact of stigma and how it may hinder women's disclosure and treatment engagement (Koniak-Griffin et al., 2006; Pinto-Foltz & Logsdon, 2008). A feminist approach to women's experience of stigma and maternal mental illness, both in theory and practice, is appropriate. For

example, according to relational-cultural theory (Miller & Stiver, 1997), all disconnections in growth-fostering relationships occur within specific socio-cultural contexts and are the source of psychological problems. Some feminist researchers have used a feminist, social constructionist approach when seeking to better understand women's experience of maternal mental illness as embedded within and influenced by the socio-cultural discourses of reproduction, motherhood and mothering (Arendell, 2000; Choi et al., 2005; Cosgrove, 2000; Mauthner, 1998). "This paradigm affords a means for looking at, and taking seriously, interactions, interpretive processes, social context, and importantly, relationships" (Arendell, 2000, p. 12) when exploring women's experience of stigma associated with maternal mental illness.

Several strategies have emerged to decrease the effects of stigma in order to improve help-seeking willingness and access to appropriate mental health services such as: a) providing education and training opportunities for health care providers to increase the knowledge about maternal mental illness and treatment options; b) providing accurate information to women and their families to enhance treatment engagement; c) increasing direct client-provider contact, interactions, and experience promoting familiarity with people with mental illness; d) and promoting a collaborative approach in providing mental health care services (Corrigan & Wassell, 2008; Kates et al., 2011; Marcus, 2009; Rockman, Salach, Gotlib, Cord, & Turner, 2004).

The study's purpose was to explore and describe women's subjective experience of maternal mental illness, accessing mental health care services, and the role stigma had in their experience. Analysis focused attention on the bio-psycho-social dimensions of their experience. According to Tufano (2000):

Within the biopsychosocial model, a client is understood from a variety of influential components that include the biological origins of disease as well as the social implications for one's environment and interpersonal experiences. From this approach, a vital concern for health care professionals is to recognize and clarify how family and societal attitudes contribute to one's disability, and how these perceptions affect both the physical and emotional course of recovery for clients within the rehabilitation process (p. 113).

### **The Present Study**

A qualitative investigation of women's experience of maternal mental health and accessing care was undertaken in order to hear women's voices and explore their lived experiences. The research design was an interpretive descriptive study (Thorne, 2008) informed by a feminist perspective (McCormick & Bunting, 2002). Semi-structured interviews with six postpartum women provided an opportunity to explore women's experiences of having a maternal mental illness, the role of stigma, and accessing mental health care. Analysis focused on the bio-psycho-social dimensions of their experiences with the intent of increasing understanding about the complexities of a clinically relevant human phenomena, and generating new insights. By gaining contextual understanding of patients' health experience, knowledge is expanded in ways intended to guide and enhance clinical practice and health outcomes.

### **Organization of Thesis**

The thesis is organized as follows. Chapter 2 presents a review of the existing literature within three areas of interest: a) maternal mental illness in terms of incidence, prevalence, risks, psycho-social factors, and barriers and facilitators to treatment; b) stigmatization of maternal mental illness in terms of social and self stigma associated with mental illness, the social



construction of motherhood, the impact of stigma on help-seeking and disclosure; and c) accessing mental health care. Chapter 3 focuses on the study's qualitative methodology, specifically interpretive description (Thorne, 2008) within health care research. In Chapter 4, findings are presented describing and exploring the similarities, differences, and shared meanings of women's lived experience of maternal mental illness, stigma, and accessing mental health care services. Further, unique findings and the interconnections between the bio-psycho-social dimensions of their experiences are described as well as participants' recommendations for mental health care and advice for other mothers with mental illness. Chapter 5 includes a discussion of findings integrated into the existing literature, conceptualization of findings using Brown's (2006) Shame Resilience Theory, strengths and limitations of the research, implications for clinical/counselling practice, and suggestions for future research.

## CHAPTER 2: LITERATURE REVIEW

The following chapter provides an overview of the research literature regarding maternal mental illness in women of childbearing years, various aspects of the stigma associated with maternal mental illness, the social construction of motherhood, and accessing mental health services. The literature reviewed has been organized into four sections: a) maternal mental illness; b) the stigmatization of maternal mental illness; and c) efforts to reduce stigma.

### **Maternal Mental Illness**

Mental illness in pregnant and postpartum women has become a public health concern which has gained attention in recent years. Several risk factors for developing maternal mental illness and various psycho-social stressors that influence its incidence and prevalence are identified in the literature, as well as the potential harmful impact of maternal mental illness on the mother, child and family unit. The use, efficacy, and safety of certain psychotropic medication and level of treatment engagement are other topics reported in the literature.

**Incidence, prevalence, and risk factors.** Depression is one of the greatest causes of worldwide maternal mental illness in women of childbearing age - approximately 15 to 44 years of age (World Health Organization, 2008). In Canada, up to seven percent of all women are affected by depression, with lifetime prevalence of 12.3%, which is increasingly becoming a major public health concern (Marcus, 2009). Recent estimates of the initial onset of depression during pregnancy range from 1.6% and 5.7% during the postpartum period; women with a history of depression have a two-fold risk of developing a major depression in the perinatal period (Banti et al., 2011), that is, occurring either during pregnancy or within the first 12 months after delivery (Gavin et al., 2005).

Maternal mental illness is most commonly associated with postpartum depression (PPD). Indeed, there is a substantial body of research literature on PPD, in comparison to other maternal mental illnesses, occurring during antepartum and/or postpartum periods. Other variants of maternal mental illness include: antepartum depression, antepartum and/or postpartum anxiety, and postpartum psychosis; however, these are often represented using the umbrella term of postpartum depression (Brockington, 2004; Marrs, Durette, Ferraro, & Cross, 2009). Some authors suggest that PPD represents a constellation of symptoms of which depression is the most recognized (Marrs et al., 2009). Psychological distress, an emotional disturbance that affects day-to-day living and social functioning, is associated with symptoms of anxiety and depression (Drapeau, Marchand, & Beaulieu-Prevost, 2012; Payton, 2009), which “becomes a medical concern when it is accompanied by other symptoms that, when added together, satisfy the diagnostic criteria for a psychiatric disorder” (Drapeau et al., 2012, p. 106). For the purpose of this study, the term maternal mental illness will be used to represent the variants of diagnosis of psycho-pathology in pregnant and postpartum women previously mentioned.

Postpartum depression refers to a major depressive disorder occurring after giving birth, which affects between 10 to 25% of women worldwide, within the first postpartum year (Brockington, 2004; Gold, 2002; Marcus, 2009; McCarthy & McMahon, 2008). Women who have previously experienced PPD have a 50% higher risk of recurrent episodes following subsequent pregnancies (Gold, 2002; Marcus, 2009). When PPD goes untreated, it may lead to the rarest and most severe form of maternal psychiatric illness, postpartum psychosis, which can affect 0.1 to 0.2% of women with maternal mental illness (Brockington, 2004; Marcus, 2009). Puerperal or maternal psychosis refers to a form of mania, severe depression with delusions, confusion, stupor, or acute polymorphic psychosis (Brockington, 2004). Women with psychosis

often experience distressing symptoms of hallucinations, delusions, confusion, are frequently hospitalized, and may pose a safety risk to themselves and their children, if left untreated. Approximately 50 to 70% of women, who have a history of psychosis with a previous pregnancy, have a higher risk of developing another psychotic episode following subsequent pregnancies (Marcus, 2009).

Antepartum depression, depression during pregnancy, impacts up to 20% of women in a primary health care setting, and 29.3% for socially high-risk (i.e., living in poverty) women (Bowen, Stewart, Baetz, & Muhajarine, 2009). Some authors suggest that prevalence rates for antepartum depression range from 4 to 57%, in different populations of pregnant women (Bennett et al., 2004; Marcus, 2009); however, other researchers indicate that prevalence rates vary significantly based on screening tools used, diagnostic criteria, and time of screening (Marcus, 2009). Bowen et al. (2012) found prevalence of depression during the first trimester at 14.1%, also 21% of women who were depressed early in their pregnancy, and 27% who were depressed in late pregnancy, continued to be depressed in postpartum (Bowen et al., 2012).

Researchers have shown that for 50% of patients being seen in primary care settings for mental health issues, anxiety and depression occurred simultaneously (Matthey, Barnett, Howie, & Kavanagh, 2003). Recent studies indicate co-morbidity between anxiety and depression is more common than previously thought (Austin et al., 2010; Bowen, Bowen, Maslany, & Muhajarine, 2008; Wardrop & Popadiuk, 2013; Yelland, Sutherland, & Brown, 2010). High levels of co-morbidity between anxiety and depression (up to 33%) have been identified in mothers with mental illness (Austin et al, 2010; Britton, 2005), which certainly highlights the importance of recognition and treatment of both issues when women present with maternal mental and emotional distress.

Maternal anxiety is usually examined in the context of women already reporting depressive symptoms (Wenzel, Haugen, Jackson, & Brendle, 2005). There is less research literature focusing on maternal anxiety which occurs during and/or after pregnancy (Britton, 2005; Ross & McLean, 2006). However, some researchers suggest that maternal anxiety is common and problematic for many women. Wenzel et al. (2005) reported prevalence rates of Generalized Anxiety Disorder to be as high as 8.2% in postpartum women. Symptoms of antenatal or postnatal anxiety may not be recognized or addressed in pregnant and postpartum women and may remain untreated/undertreated as a result (Bandelow et al., 2006; Britton, 2005; Wardrop & Popadiuk, 2013). Britton and colleagues found that 24.9% of women had a moderate amount of pre-discharge anxiety and 1% had severe anxiety (Britton, 2005). Matthey et al. (2003) asserted that when conceptualization of poor psychological adjustment includes anxiety, prevalence rates of maternal psychiatric illness increase significantly. Treating anxiety during pregnancy may prevent the development of PPD in some women (Austin et al., 2007). Some researchers found that the postpartum period seemed to increase the risk for the onset and/or the exacerbation of panic symptoms in women (Bandelow et al., 2006). Women who reported stress during pregnancy had a higher risk of panic symptoms (Bandelow et al., 2006).

Anxiety disorders are the most prevalent psychiatric disorders, affecting about 16% of Canadian women, with up to 30% lifetime prevalence (Health Canada, 2002). Anxiety disorders in women commonly occur in their mid-20s (Pigott, 2003). Pre-existing anxiety/panic disorders often persist or worsen with pregnancy (Bandelow et al., 2006; Gold, 2002). Women who experience prenatal anxiety are three times more likely to report severe PPD symptoms, compared to women without anxiety (Austin et al., 2007; Bowen et al., 2008). Further, a history of an anxiety disorder appears to be associated with a greater risk for developing postpartum

anxiety and/or depression, than does a history of a depressive disorder (Matthey et al., 2003). In addition, a history of depression and mood fluctuations may increase the risk for developing anxiety (Bowen et al., 2008). Anxiety might also increase because psychosocial stressors play a significant etiological role in the development of anxiety, for those who have a vulnerability (Wenzel, Haugen, Jackson, & Robinson, 2003). For instance, Bowen and colleagues (2008) found that anxiety symptoms may be more predominant than depressive symptoms in socially high-risk pregnant women; and younger pregnant women may be at a higher risk for developing anxiety than older ones.

It is also important to consider pre-existing mental illness, such as bipolar disorder, when dealing with women's mental health during and after pregnancy. Bipolar disorder affects 1-2% of the population, and often occurs in women during childbearing years, making them extremely vulnerable during the postpartum period, with a rate of relapse estimated at 33-50% (Gold, 2002).

Some authors claim that few screening assessment instruments are sensitive enough to indicate or differentiate between maternal mental illnesses (Matthey, 2008; Wardrop & Popadiuk, 2013). Despite the evidence of anxiety and depression co-morbidity in maternal mental illness, there is less research and inconsistent protocols regarding anxiety screening; as well, there are few tools sensitive enough to assess for various forms of anxiety (Wardrop & Popadiuk, 2013). However, some researchers found that anxiety symptoms in pregnant and postpartum women were detected using the Edinburgh Postnatal Depression Scale (EPDS) as a multi-factorial screening tool to measure maternal anxiety (Austin et al., 2007; Bowen et al., 2008).

Several bio-psycho-social risk factors are associated with the development of maternal mental illness: personal or family history of affective disorders; prior history of PPD or postpartum psychosis; lack of social support; single marital status; lower socio-economic status; poor health functioning; unplanned pregnancy; relationships issues; stressful life events during or near the time of delivery; substance abuse; and a difficult pregnancy (Gold, 2002; Kalra & Einarson, 2006; Marcus, 2009).

**Bio-psycho-social factors of maternal mental illness.** Women who suffer from prolonged and/or undertreated maternal mental illness are less likely to breastfeed and have an increased risk of biological/biomedical complications during pregnancy such as: spontaneous abortion and pre-eclampsia, higher rates of surgical deliveries, and epidural use (Bonari et al., 2004; Marcus, 2009). Furthermore, it is more likely that newborns of women with significant maternal mental illness will experience negative outcomes such as: preterm birth, increased admission to the neonatal intensive care unit, lower birth weight; decreased Apgar scores, smaller head circumference, feeding and sleep problems, and lower gestational age (Marcus, 2009).

Several psycho-social factors and untreated or severe maternal mental illness have profound bio-psycho-social effects, not only on the new mother and baby, but also on her partner and other relationships. Children of mothers who experienced depression and anxiety, during or after pregnancy, often exhibit difficulties with psychological adjustment and development such as: negative emotional, social and cognitive development, delayed language and intellectual abilities, insecure attachment, and have psychopathological difficulties, such as Attention-Deficit Hyperactivity Disorder (ADHD), autism, schizophrenia, and affective disorders (Gold, 2002; Marcus, 2009; Talge, Neal, & Glover, 2007). The incidence of paternal depression during the

first postpartum year ranged from 1.2% to 25.5% in community samples, and from 24% to 50% among men whose spouse had PPD (Goodman, 2004). The strongest predictor of depression in fathers during postpartum was the presence of PPD in their spouse (Goodman, 2004). Untreated PPD also increases a mother's risk for ongoing maternal mental illness, which often results in poor mother-child interactions affecting the child's attachment, temperament, and behavioural/cognitive development (Da Costa, Dritsa, Rippen, Lowensteyn, & Khalifa, 2006; Gold, 2002). Furthermore, failure to address maternal mental illness leaves women more vulnerable to chronic depression greatly impacting a mother's opportunity for recovery and wellness, which may interfere with her ability to mother, often with the added challenge of parenting a child with emotional/behavioral difficulties (Matthey et al., 2003; Seto et al., 2005). Chronicity of maternal mental illness has a significant negative impact on a woman's quality of life, physical and emotional well-being, social interactions, self-care and sleep quality (Bowen et al., 2012; Da Costa et al., 2006; Seto et al., 2005). Indeed, the lack of detection and treatment of maternal mental illness has devastating and long-lasting bio-psycho-social implications for the mother, the baby, and the family unit.

**Treatment of maternal mental illness.** Many people in our society believe that pregnant women should not take any medication (Einarson, 2009b). There is controversy surrounding pharmacological treatment for pregnant and postpartum women (Einarson, 2009b, 2010; Wisner et al., 2009), but also limited research on alternative options for treating maternal mental illness. Although research indicates the frequency and potential negative effects of maternal mental illness are an increasing concern, symptoms of anxiety and depression in pregnant and postpartum women are often overlooked by primary health care providers as well as the women themselves (Cohen & Nonacs, 2005; Gold, 2002; Marcus, 2009). However, for a woman who is



anxious and/or depressed taking medication may be necessary to alleviate distressing symptoms and circumvent negative effects on herself and her baby. Some researchers estimate 3% to 13% of pregnant women take psychotropic medication during pregnancy (Bowen et al., 2012; Cooper, Willy, Pont, & Ray, 2007; Wisner et al., 2009). Several antidepressants have demonstrated safety for use during pregnancy with rates of major malformations in the fetus at 2.5% in pregnancies, and within the rate of spontaneous risk in the general population at 1% to 3% (Einarson, Choi, Einarson, & Koren, 2009).

Cohen et al. (2006) found a 68% risk of relapse among pregnant women who discontinue existing antidepressant treatment. Although evidence-based information regarding the efficacy and safety of using certain antidepressants during or after pregnancy is readily available, researchers found that there was a tendency among health care providers to be overly cautious and to under-treat pregnant women (Cohen et al., 2006; Einarson, 2009b). It is important to weigh the risks and benefits to both mother and baby when using psychotropic medication to treat maternal mental illness. The mother's previous history of mental illness, present functioning, and risk for developing more severe symptoms need to be considered (Einarson et al., 2009; Yonkers et al., 2009).

**Diagnosis and treatment engagement.** Diagnosis and treatment engagement are important topics because untreated or undertreated maternal mental illness increases the risk of unfavourable pregnancy outcomes for the mother and child (Marcus, 2009). Treatment engagement is understood as taking psychotropic medication as prescribed and tends to increase when women are screened by their health care provider and informed about their depressive state (Marcus, 2009). Mothers are reluctant to disclose feelings of emotional and mental distress without having the question asked first by their physician (Dennis & Chung-Lee, 2006).

According to Pinto-Foltz and Logsdon (2008), few postpartum women receive treatment despite screening and referrals. According to several researchers, pregnant and postpartum women with mental health problems often do not seek and/or receive adequate mental health care due to the following: a lack of personal insight and awareness of symptoms; a lack of knowledge of PPD; denying or minimizing their feelings of distress; a lack of and/or limited access to mental health care services; and the under-diagnosis by health care providers who tend to minimize and may not recognize women's depressive symptoms (Dennis & Chung-Lee, 2006; Gold, 2002; Marcus, 2009; Pinto-Foltz & Logsdon, 2008; Sobey, 2002). Further, the controversy surrounding the use of psychotropic medication in pregnant and postpartum women contributes to high anxiety levels not only among women, but also their health care providers (Einarson, 2010).

Some women might decide not to seek care or fully participate in care as a means of avoiding the label associated with a diagnosis of mental illness - *label avoidance* (Corrigan, 2004). However, for some women, a diagnosis provides a sense of relief and reassurance because they perceive it as confirming a medically recognized problem, rather than being a result of personal defect or inadequacy, which releases them from self blame and responsibility (Edwards & Timmons, 2005; Mauthner, 1998). Feeling stigmatized was part of the women's experience of reaching out for help for maternal mental illness (McCarthy & McMahon, 2008). Qualitative research on the lived experience of women suffering with and seeking care for maternal mental health problems revealed several help-seeking barriers: lack of knowledge of PPD and/or lack of insight and awareness of symptoms; aspects of stigma associated with maternal mental illness; feelings of shame and being a bad mother; and a fear of disclosing (Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005; McCarthy & McMahon, 2008; Pinto-Foltz & Logsdon, 2008).

## Stigmatization of Maternal Mental Illness

Stigma is ubiquitous, multidimensional, and embedded in a socio-cultural context; it is experienced in all cultures and encountered in various stages of life (Hinshaw & Stier, 2008; Pinto-Foltz & Logsdon, 2008). Each society defines what is *normal* and socially acceptable, or unacceptable, and open to stigmatization (Goffman, 1963; Pinto-Foltz & Logsdon, 2008). Stigma is a social construction which refers to a mark, flaw, or spoiled identity resulting from a personal characteristic or attribute, viewed as socially undesirable, and perceived as deviant, different, defective, and to be discounted (Goffman, 1963; Stuenkel & Wong, 2009). Stigma experienced externally, *social/public stigma*, is associated with socially-held and collectively agreed upon beliefs and preconceptions which become stereotypes that serve to characterize, categorize, and label the stigmatized person or group (Corrigan & Wassell, 2008; Corrigan & Watson, 2007; Kenny, 2001). Prejudice occurs when one agrees with existing stereotypes (stereotype agreement) and applies it to an individual (stereotype application), which results in a negative evaluation and may lead to discrimination (Corrigan & Wassell, 2008). Discrimination refers to a behavioural reaction and the unfair evaluation and treatment from others, as a result of prejudice (Corrigan & Wassell, 2008); this is also referred to as *enacted stigma* (Green et al., 2003; Stuenkel & Wong, 2009).

Internal stigma, or *self stigma*, refers to the effects of identifying with and internalizing negative social stereotypes and misconceptions which impact individuals both cognitively and behaviourally (Corrigan & Wassell, 2008; Kenny, 2001). Identification involves not only the awareness of existing negative stereotypes, but also indicates an element of agreement with these negative misconceptions and then applying these to one's self; internalization involves the integration of social attitudes, beliefs, and expectations into one's sense of self (Goffman, 1963).

Consequently, individuals may experience self stigma as a self-devaluation, a loss of self-esteem and self-efficacy and will often struggle with a positive self-concept (Corrigan et al., 2009) as they may internalize feelings of shame and being a bad mother (Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005; McCarthy & McMahon, 2008; Pinto-Foltz & Logsdon, 2008). Self-efficacy is a person's belief and confidence in their own ability to manage various life situations (Bandura, 1977, 1994). Decreased self-esteem and self-efficacy may result in a *why try* response which is an unwillingness to engage in various aspects of life, or to seek help and access appropriate care, in order to avoid the negative impact of stigma (Corrigan et al., 2009). Further, *perceived stigma*, which refers to an individual's internalized perception of being devalued, judged, or rejected by others, brings about feelings of shame, embarrassment, and fear of being labelled and treated differently (*felt stigma*), even though the stigmatized characteristic/attribute is not known or apparent (Green et al., 2003); that is, "individuals view themselves as discreditable" (Stuenkel & Wong, 2009). Self stigma is often associated with negative emotional reactions, such as shame, anger, fear, anxiety, low self-esteem and low self-efficacy (Corrigan, Watson, & Barr, 2006), self-blame, guilt, remorse, and feelings of being self-indulgent (Kenny, 2001). However, just because people are aware of the stigma of mental illness does not necessarily mean that they will internalize it and suffer a decrease in self-esteem and self-efficacy (Corrigan et al., 2006).

**Stigma of mental illness.** Stigma has many nuances, exists as a matter of degree, and has deeply embedded historical/cultural roots, such as the stigma surrounding mental illness. Because of prevailing societal beliefs, people living with mental illness are viewed through a discriminatory and prejudicial lens. The stigma of mental illness refers to "a collection of negative attitudes, beliefs, thoughts, and behaviors that influence the individual, or the general

public, to fear, reject, avoid, be prejudiced, and discriminated against people with mental disorders” (Gary, 2005, p. 980). According to Kenny (2001), the term mental illness has been linked to descriptors which serve as labels, such as *crazy* or *mad*, and linked to negative stereotypes and misconceptions of people with mental illness as being dangerous, unpredictable, unreliable, unlikeable, incompetent, and bizarre; hence they are to be feared. People with mental illness are viewed as more blameworthy than those with physical conditions; are often perceived as being in control of their illness, responsible for causing it, or having brought it upon themselves; and viewed as a manifestation of unacceptable behaviour or immoral character, or as having a poor prognosis (Corrigan & Watson, 2007).

Corrigan and Wassell (2008) described mental illness as a double-edged sword since people not only experience disabling symptoms and emotional distress, but also personal demoralization, as a result of stigma. Stigma of mental illness is the result of ignorance and misunderstanding surrounding the origin, symptoms, nature and presentation of psychiatric illness (Kenny, 2001). Many individuals with mental illness do not seek mental health care to avoid being diagnosed with a psychiatric illness, and being marked with the label *crazy* or *mad*, and thus, escaping the negative effects of social and self stigma (Corrigan & Wassell, 2008). This *label avoidance* is manifested as concern about being stigmatized, judged, misunderstood, and rejected, that is, perceived stigma (Corrigan & Wassell, 2008; Kenny, 2001).

Research indicates that self stigma is the main obstacle that prevents many women living with mental illness from seeking help and having a chance for recovery as they often have feelings of embarrassment and shame and fear being judged (Corrigan & Wassell, 2008; Edwards & Timmons, 2005; Halter, 2004; Kenny, 2001; Tognazzini et al., 2008). “The harsh

reality is that [people with mental illness] suffer in silence and their lives reflect the invisible pain and suffering that stigma causes” (Tognazzini et al., 2008. p. 30).

**Social construction of motherhood.** Pregnant and postpartum women living with mental illness are not only affected by symptoms of psychological and emotional distress, and by the effects associated with the stigmatization of mental illness, but they are also embedded in society’s notions of *motherhood*, and what it means to be a woman with a reproductive body. The stigma associated with *maternal* mental illness reflects a deeper, more entrenched social *zeitgeist*, a very gender-specific one which defines what it means to be a woman, and a mother. Motherhood is a construct that is culturally defined within social, economic and historical contexts (Francis-Connolly, 2000; Nicolson, 1999; Woollett & Boyle, 2000). Woollett and Boyle (2000) described the social construction of motherhood:

Motherhood is constituted as compulsory, normal and natural for women, for their adult identities and personal development, and is regulated through binary oppositions in which the warm, caring and ‘good’ mother is contrasted with ‘bad’ mothers, selfish, childless, and career women, and empty and deficient infertile women (p. 309).

The idealized view of *good mother* has roots in the 19<sup>th</sup> century and remains the social measuring stick by which many mothers gauge their real-life experiences (Koniak-Griffin et al., 2006; Nicolson, 1999). At an early age, acceptable social gender norms are learned and often fostered in the family system, hence, it is almost impossible to remain uninfluenced by the social scripts dictating what it means to be a woman, mother, and wife. Women’s gender identity is reinforced by the social and traditional preconceptions of motherhood and the onerous expectations of *joyful mothering* (Arendell, 2000; Koniak-Griffin et al., 2006). Indeed, our society endorses self-identification with negative conceptions of mental illness through the use of

language and the media (Wahl, 2003). Media, in various forms, is the major source of information on health and illness for most people, and thus plays an important role in shaping attitudes and beliefs, for better or worse; however, it also serves to maintain and perpetuate the negative stereotypes and images of maternal mental illness.

Adrienne Rich's classic feminist research (1986/1997) described the image of *good mother* as a woman whose sole identity is motherhood. Mothering is considered as the ultimate fulfillment and the essence of womanliness and femininity (Arendell, 2000; Koniak-Griffin et al., 2006). This is in contrast to the stereotype of the *bad mother* which entails the notion that good women (i.e., normal) do not show aggression, rage, hostility, anger, violence, or short tempers (Chrisler & Johnston-Robledo, 2002) which translates into mothers should be happy, calm, content, and grateful.

Historically, scientific and biomedical discourses have informed the traditional, social, and biological conception of motherhood as women's primary function views women as essentially a set of reproductive organs with a body, helped perpetuate the myths of motherhood and mothering as being an easy, natural, normal and wonderful experience, the peak of women's achievements, the greatest joy in a woman's life, and the only reason for their existence (Cosgrove, 2000; Koniak-Griffin et al., 2006; Nicolson, 1999). Moreover, the notion of *maternal instinct* implies that all women naturally desire and give birth to children, that they will know how and want to care for them, which leaves little room for individual differences amongst women's experience of motherhood and mothering within their socio-cultural context (Choi et al., 2005; Nicolson, 1999). *Intensive mothering* was a term coined to describe the dominant expectations of Western mothers as the ideal and preferred caregivers for children and devoted to the care of others, self-sacrificing, without needs and interests, and the good mother (Arendell,

2000). Furthermore, in today's Western society, cultural representations of womanhood has expanded to include the notion that today's woman can do it all, have it all, and manage it all - a *superwoman* or *supermom* who is able to cope with the numerous competing demands of family and work (Choi et al., 2005; Francis-Connolly, 2000) and doing it all with a smile.

Unfortunately, the reality of motherhood is very different from the myth. The notions of the perfect mother who does not need help to cope and manage mothering have possible deleterious effects on women suffering from maternal mental health problems. Asking for help or feeling unable to cope is difficult because of an underlying belief that mothers should be happy and able to cope without help, which creates dissonance between reality and actuality (Choi et al., 2005; Nicolson, 1999). *Maternal ambivalence* is grounded in this paradoxical nature of the experience of mothering as being both positive and negative (Arendell, 2000).

Ambivalence refers to a pervasive state of existence encompassing cognitive, behavioral and emotional being (Leichtentritt, Blumenthal, Elyassi, & Rotmensch, 2005). Several researchers identified ambivalence as an over-arching theme in some women's experience of maternal mental health problems (Leichtentritt et al., 2005; McKillop, 2009). The ambivalence was found between their experience and feelings of women with mental health problems and their perception of the social expectations and the myth of motherhood. *Mother blaming* refers to a type of enacted and/or felt stigma which blames the mother for undesirable outcomes (e.g., children with emotional/behavioural problems or birth/physical defects) independent of her choices which make mothers with mental illness subject to prejudice, discrimination, and discredit from others (Koniak-Griffin et al., 2006). Subsequently, the self stigma associated with being a *woman* with a mental illness is inextricably linked to her socio-cultural milieu.



**Stigma of maternal mental illness.** According to Pinto-Foltz and Logsdon (2008), several characteristics are related to self stigma associated with maternal mental illness such as: an unpleasant personal experience; self-identification; permanency; a perceived unfavourable attitude from others; label attachment; feeling of being discredited by others for being viewed as deviant and inferior to the norm; and discrimination by others when attempting to assume a normative role. The internalized sense of being a bad and/or unfit mother, or being perceived by others as being a less-than-perfect mother, exemplifies a deeper and more pernicious stigmatization associated with being a *woman* with a mental illness and her ability to mother. The depth of self stigma depends on the degree of identification and internalization of negative social stigma associated with maternal mental illness and unrealistic expectations of motherhood which undermine a sense of self-esteem, and thus self-efficacy (Corrigan et al., 2009).

Self-identification with negative stereotypes of mental illness and cultural myths surrounding motherhood can result in feelings of inadequacy and negative self-evaluation, which in turn, result in the fear of disclosure. Under-reporting of distressing symptoms is common as women do not want to be perceived as bad mothers and fear having children apprehended were they to reveal the level of their emotional distress and admit being unable to manage their symptoms of mental illness and cope with the demands of mothering (Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005; Einarson, 2009b; Marcus, 2009; McCarthy & McMahon, 2008).

**Seeking care.** Fear of disclosure due to self stigma and perceived stigma is recognized as the main barrier for women seeking help for maternal mental illness (Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005; Einarson, 2009b; Marcus, 2009; McCarthy & McMahon, 2008). Some authors found disclosure to be related to perceived stigma, perceived social support

and self-esteem (Bos, Kanner, Muris, Janssen, & Mayer, 2009). A qualitative systematic review conducted by Dennis and Chung-Lee (2006) found women's rationales for lack of disclosure were diverse and included reasons such as: thinking that they could or were expected to cope with depression; not wanting to be burdensome; giving their family a bad name and risking being seen as responsible for problems in the family; fear of having children taken away; and to avoid shame, perceived and enacted stigma and fear of being labelled mentally ill.

Pinto-Foltz and Logsdon (2008) found the amount of perceived control a person has over their condition was highly correlated with stigmatization. People were less likely to experience self stigma when they believed they were in control of their lives and their treatment (Corrigan & Wassell, 2008). Self disclosure is a means of managing information about personal failings that may be subject to stigma: that is, having control by deciding "to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where" (Goffman, 1963, p. 42). Disclosure of mental health status, which is coming out to others, may benefit some people who selectively disclose (Bos et al., 2009; Corrigan & Wassell, 2008). *Selective disclosure* is when a person with mental illness decides to let only some people know about their mental illness (Corrigan & Wassell, 2008). On the other hand, coming out may lead to disapproval from others, which may lead to social avoidance (Corrigan et al., 2009).

As a way to avoid the deleterious effects of stigma, some people choose *secrecy* - withholding information and not letting anyone know about their mental health history (Corrigan & Wassell, 2008). Others will attempt to pass as normal; *passing* refers to a type of covering which involves an effort to restrict or conceal any display that may identify the stigma (Goffman, 1963; Corrigan et al., 2009). However, secrecy and passing can have a psychological cost in that there always remains a fear of discovery (Goffman, 1963). The lack of disclosure of distressing

symptoms of mental illness greatly impinges on a woman's ability to access and receive the appropriate level of mental health care.

**Stigma and health care providers.** Another deterrent to seeking care for maternal mental illness can be negative interactions with health care providers. Studies indicate that health care professionals and students, such as doctors, pharmacists, and nurses, may hold stigmatizing views towards women with maternal mental illness, despite having training expected to enhance acceptance of patients with mental health (Gawley, Einarson, & Bowen, 2011; Thornicroft, Rose, & Kassam, 2007; Tognazzini et al., 2008). According to Pinto-Foltz and Logsdon (2008):

Stigma is poorly understood and often remains unrecognized by nurses [and other health care providers] within themselves and others. Unrecognized stigma is a barrier to understanding patient behavior and providing individualized emphatic care (p. 22).

New mothers have reported various experiences of stigmatization when seeking help for mental illness problems and hesitancy about mental health services (Ahmed et al., 2008; Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005; McCarthy & McMahon, 2008; Pinto-Foltz & Logsdon, 2008). Women reported feeling stigmatized by attitudes of some health care providers who minimized or were reluctant to respond to their emotional and practical needs and concerns, which impacted access to mental health services and the level of care received (Ahmed et al., 2008; Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005).

Additional health care barriers to seeking help for maternal mental illness include: inappropriate or lack of assessment; insufficient training and lack of knowledge about PPD and treatment safety; perceived dismissive attitudes of health care providers; tendency to minimize or overlook symptoms of maternal psychological distress; having insufficient time during

consultation; tendency to prescribe medication, rather than talk, to alleviate symptoms reinforcing feelings of women inadequacy; as well as fearing implied weakness or perceived failure (Dennis & Chung-Lee, 2006; McCarthy & McMahon, 2008).

Educational opportunities to promote more knowledge, familiarity and understanding of maternal mental illness are needed to circumvent the stigma of mental illness (Corrigan & Wassell, 2008; Rockman et al., 2004; Schulze, 2007; Thornicroft et al., 2007; Tognazzini et al., 2008). In particular, researchers suggest that more needs to be done to educate health care professionals and students about the symptoms, treatment and consequences of maternal mental health on mother, baby and family; to increase awareness, understanding, and sensitivity of the negative impact of stigmatization; and to understand how self stigma and perceived stigma hinders women's disclosure and treatment engagement (Koniak-Griffin et al., 2006; Thornicroft et al., 2007; Tognazzini et al., 2008).

### **Efforts to Reduce the Stigma of Maternal Mental Illness**

**Education and contact.** Researchers suggest three strategies to decrease the effects of stigma in order to improve help-seeking willingness and access to appropriate mental health care services: protest, education, and contact (Corrigan & Wassell, 2008). Protest is a reactive strategy that aims to diminish the negative attitudes about mental illness by promoting more positive attitudes supported by facts (Corrigan & Wassell, 2008). Education challenges social misconceptions about mental illness by providing accurate information to those living with mental illness, their families, and their health care providers (Corrigan & Wassell, 2008). Providing education to women and their families to better inform them about maternal mental illness, treatment options, and the risks/signs of PPD is recognized as a major help-seeking facilitator (Cohen & Nonacs, 2005; Dennis & Chung-Lee, 2006). People with more years of

education are likely to have more knowledge about and/or experience with mental illness, which in turn leads to less stigmatization (Arvaniti et al., 2009; Corrigan & Watson, 2007). Continued education within the health care system is needed to promote positive messages and accurate information about people with mental illness and to increase awareness of and sensitivity to the impact of stigma (Corrigan & Watson, 2007; Kenny, 2001). Health care providers need to keep abreast of current research to be knowledgeable about maternal mental illness, its treatment, and the role stigma plays in women's experience of seeking help (Dennis & Chung-Lee, 2006; Koniak-Griffin et al., 2006).

Contact or familiarity refers to knowledge of and experience with mental illness, which has the best impact of the three strategies to reduce stigma (Corrigan & Watson, 2007). Open interactions with people with mental illness during training allow health care providers to learn about patients' lived experience and gain insight into how illness and stigma impacts their life (Tognazzini et al., 2008). Familiarity with people with mental illness coupled with small amounts of targeted education was more effective in lowering stigma than contact alone (Corrigan & Wassell, 2008; Corrigan & Watson, 2007). Health care providers should also strive to be aware of their own perceptions of mothers with mental health concerns and how these might contribute to stigmatization (Kenny, 2001; Koniak-Griffin et al., 2006).

Researchers have highlighted the importance of a collaborative approach between primary health care providers and mental health professionals to provide mental health care to women living with mental illness, has been shown to decrease stigma, increase client and health care provider satisfaction, and decrease use of traditional mental health services (Bowen et al., 2008; Kates et al., 2011; Rockman et al., 2004). Primary health care refers to basic health care programs and services and signifies an individual's first contact with the health care system,

usually with family physicians (Bowen et al., 2008; Canadian Collaborative Mental Health Initiative, 2006; Rockman et al., 2004). Research indicates that women with maternal mental illness are more likely to seek help from primary health care providers than mental health professionals (Gold, 2002). Women with mental illness report less stigma when accessing mental health care in a primary care setting; and their children with emotional/behavioural problems were four times as likely to be identified and treated (Weissman et al., 2004). Further, rates of treatment engagement increase modestly when women were screened by their health care provider and informed that their depression/psychological status was indicative of maternal mental illness (Marcus, 2009).

Some authors found that family physicians with access to a collaborative mental health care report greater knowledge, better skills, more comfort in managing psychiatric disorders, and greater satisfaction with mental health services (Kisely, Duerden, Shaddick, & Jayabarathan, 2006). Researchers identify the need for mental health care programs based on the shared care model which incorporate opportunities for educating health care professionals, are meant to improve women's access to psychiatric care and consultation, and promote collaboration, consultation, and respect amongst primary care providers and psychiatrists (Bowen et al., 2008; Kates et al., 2011; Rockman et al., 2004). The key elements of collaborative partnership between health care providers entail: effective communication, consultation, coordination, co-location, and integration (Kates et al., 2011).

## **Summary**

Mental illness in pregnant and postpartum women has become a growing public health concern. Prolonged and/or under treatment has bio-psycho-social effects/implications for mother, baby and family yet pregnant and postpartum women with mental health problems often receive

inadequate mental health care and/or do not seek help. Listening to women's voices and exploring their lived experiences of accessing maternal mental health care and stigmatization adds to the current literature, which is primarily biomedical in nature and uses quantitative research methods. Thus a qualitative inquiry was undertaken informed by the following research question: What are women's lived experiences of maternal mental illness, stigma and accessing mental health care?

## CHAPTER 3: METHODOLOGY

This chapter presents a description of and a rationale for using a qualitative health research approach within a feminist framework. The research method, interpretive description (Thorne, 2008), is described and the research design logic is presented by situating the study and the researcher. Procedures for recruitment, data generation, and data analysis are presented. Lastly, evaluation criteria and ethical considerations are discussed.

### **Qualitative Inquiry**

Qualitative inquiry encompasses a wide range of philosophical/epistemological positions, methodological approaches, and analytical processes. However, all qualitative inquiries seek to understand the meaning that individuals construct from their own lived experiences and social interactions, which cannot be quantified, measured, or de-contextualized (Denzin & Lincoln, 2000; Kearney, 2001). This interpretive and naturalistic approach is based on the following characteristics: validating subjectivity; acknowledging multiple realities; expanding knowledge through discovery, description, and understanding; collaborating with participants; being embedded in a context; and exploring with an emergent flexible design, using inductive analysis (Denzin & Lincoln, 2000; Kearney, 2001; Thorne, 2008).

**Qualitative health research.** In order to improve patients' quality of care and enhance health care practice, clinical health researchers often quest for knowledge that can be applied to real people living with complex and difficult health problems (Kearney, 2001; Thorne, 2008). Qualitative health researchers seek to explore and understand complexities and generate new insights about the experience of clinically relevant human phenomena (Thorne, 2008). Applied qualitative health research is concerned with investigating questions from the field to gain sufficient contextual understanding of patients' health experience in order to apply expanded



knowledge in ways that could guide and enhance clinical practice (Thorne, 2008; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). In this way, new insights could offer clinicians a set of possibilities for clinical exploration, increase awareness of problems to watch out for, and deepen sensitivity to and understanding of patients' illness experience, behaviours, and choices (Kearney, 2001; Thorne, 2008).

### **Interpretive Description**

The research method for this study, interpretive description (Thorne, 2008), was particularly suited to applied clinical health research using the subjective experiential knowledge of women living with maternal mental illness, stigma and accessing mental health care services. Thorne (2008) differentiated interpretive description from other qualitative inquiry, in that it provides a reasoned approach to knowledge development in the applied health care field, with the purpose of expanding capacity for understanding implications of phenomena in clinical practice, and to better informing care of the unique and distinct individual. This approach allows applied qualitative health researchers the flexibility to deconstruct the lens of previous knowledge, provide an alternate perspective, generate new insights and new questions, and apply evidence to clinical practice (Thorne, 2008).

Several of the defining features of interpretive description were particularly well-suited to for the design of this study. Interpretive description: a) provided a coherent methodological framework within which a fairly wide range of options could be used for research design and implementation, data collection and analysis; b) considered knowledge as socially constructed and acknowledged multiple perspectives; c) accounted for the impact of cultural and social forces; d) sought to articulate themes, associations, and patterns of experience, action and expression; and e) interpretations were illuminated through inductive analysis of descriptive data

provided by participants who share their subjective experiences about a clinical phenomenon (Thorne, 2008). Further, these features make this approach conducive to a feminist analysis of women's experience of maternal mental illness, stigma, and accessing care.

Using an interpretive descriptive approach for this research allowed the capture of not only the complexity and uniqueness of individual women's experience of maternal mental illness, stigma, and accessing mental health care, but also allowed the intricacies and interconnections between bio-psycho-social dimensions of experience to be explored.

## **Research Design**

According to Thorne (2008), different kinds of knowledge are derived from different approaches and what we seek to understand ought to guide methodological selection. The rationale for and the quality of the research endeavour using interpretive description, depends upon the match between: first, the knowledge sought, the research question, and the methodological approach; and second, how this research design logic matches the researcher's disciplinary orientation, epistemological stance and theoretical lens, background knowledge of the phenomena, and personal experience (Thorne, 2008). Hence, the importance of two critical elements in an interpretive description research design: a) situating the study based on an literature review which determines what is currently known about the phenomenon being studied, what methods were used to gain that knowledge, and what kinds of understandings were derived; and b) situating the researcher within a theoretical framework which takes into consideration the researcher's disciplinary orientation, epistemological standpoint, and background knowledge of the phenomenon being studied (Thorne, 2008).

**Situating the study.** The review of the literature revealed the significant and far-reaching implications of untreated/undertreated maternal mental illness on mothers, their children, and the

family unit. Further, researchers found many women often receive inadequate mental health care and/or do not seek help for various reasons (discussed in Chapter 2). One of the greatest barriers to seeking care was the stigma associated with it. The present study's goal was to uncover new knowledge about this particular population of women using a feminist lens to better understand the "subjective, experiential, tacit, and patterned aspects" (Thorne, 2008, p. 36) of their experience of maternal mental illness, stigma, and accessing mental health care services. Using interpretive description was well suited to an exploration of women's experience and illuminated aspects of care that the women identified as influencing their treatment engagement/satisfaction and health outcomes.

**Feminist research.** A feminist framework was used in this study to explore women's experience of maternal mental illness in their private/personal life and within their socio-cultural context as women's subjective experiences are both defined and shaped by their networks of relationships and interconnections (Cosgrove, 2000; Mauthner, 1998; Thorne & Varcoe, 1998). As such, stigma and maternal mental illness can be understood as a gendered issue that requires a feminist approach, both in theory and practice. The goal of feminist research is to capture, explore, and understand women's experiences from the vantage point of a particular group of women (Campbell & Bunting, 1991). McCormick and Bunting (2002) summarized the common characteristics of feminist research:

- a) valuing of women and attaching validity to their experiences, ideas, and needs;
- b) recognition of the conditions that oppress women;
- c) desire to bring about social change through criticisms and political action;
- d) women and issues of gender are the central concern;

- e) research questions and answers are for the benefit of some groups of women rather than simply about women;
- f) women's current and historical context relevant to the research variables (e.g., reproduction, political implications) are recognized;
- g) there is an emphasis on subjectivity and women's context of experiences;
- h) there is a collegiality and mutual dialogue between different levels of the research team and between the researchers and the participant women;
- i) interactions are non-hierarchical in nature and structure;
- j) reflexivity, the self-questioning of the researchers' assumptions and biases, is ongoing;
- k) flexible open boundaries are honored;
- l) there is a recognition that bias is impossible to eliminate completely (p. 822).

Feminist researchers have illuminated the importance of using a feminist, social constructionist approach when exploring and seeking to better understand women's experience of maternal mental illness embedded and influenced by the socio-cultural discourses of motherhood and mothering (Arendell, 2000; Choi et al., 2005; Cosgrove, 2000; Mauthner, 1998). Further, feminist researchers/theorists such as Miller and Stiver (1997) understand that all disconnections in growth-fostering relationships occur within specific socio-cultural contexts and are the source of psychological problems, as in relational-cultural theory. Uncovering and deconstructing the meaning of living with maternal mental illness requires an interpretive understanding that seeks to discover patterns, relationships, and associations within the unique experiences being described (Kearney, 2001; Thorne, 2008).

**Situating the researcher.** Thorne (2008) explained the importance of revealing one's disciplinary background, epistemological stance, theoretical understandings of the phenomenon, and personal experience as a way to lend integrity and clarity of purpose to the research process. The researcher is the instrument by which data are collected, analyzed, categorized, described, and interpreted. Hence, it is important for the reader to be informed about the researcher's intellectual positioning and theoretical orientations, as well as for the researcher to minimize any unintended impact on the research.

My diverse undergraduate and graduate academic background has led to a multi-disciplinary orientation that encompasses the health sciences and clinical healthcare practice, philosophy and feminist studies, as well as counselling psychology. Having a health science background has provided me with an understanding of the biomedical model of health and illness, which helps me appreciate the knowledge gained by medical research and its application to clinical practice. I also believe that scientific and biomedical discourses have had a great influence on socio-cultural discourses. Consequently, I ascribe to a more holistic view of health and wellness that encompasses a bio-psycho-social model within a socio-cultural context. As a result, I consider knowledge development not only to benefit from quantitative inquiry, but also consider qualitative inquiry to be necessary to expand existing knowledge, adding depth and understanding of subjective, experiential, and socially constructed human experiences.

My epistemological stance and theoretical lens are founded on a relational-cultural ontology and a feminist, social constructionist view of knowledge development. Hence, the meaning we make of experiences is constructed through historical/cultural influences and social practices, processes, and institutions, as well as through interactions and encounters with people,

culture, and the media. That is, reality is neither fixed nor measurable, but rather composed of multiple realities, constructions, and interpretations that fluctuate with time and place.

My research interest in women's issues, specifically mental health and wellness, began with my introduction to feminist studies. Being a feminist has influenced my epistemology, methodology, worldview, praxis and psycho-therapeutic approach, and my way of being-in-the-world. My feminist and therapeutic orientation is based on a relational and empowerment approach. As a feminist researcher, I take into consideration historical influences and the socio-political landscape in which women find themselves and how these factors influence their experience of mental health, stigma, and seeking help, in addition to the impact of the psycho-social aspects and implications. I believe that the personal is political and that in order to further understanding women's experiences, women's stories need to be explored, and women's voices need to be heard. I also realize that my early research interest in women's mental health and wellness stemmed from my desire to better understand my own experience.

Due to my experience and personal struggles with maternal mental health problems, I feel strongly about bringing deeper awareness and understanding of maternal mental illness, and the impact stigma has on women's self-perception and everyday life. Through my studies and research, I began to understand motherhood on many different levels and to see that being a woman/mother with mental illness was a gendered issue, socially constructed and influenced by history, culture, and context, and that the many bio-psycho-social factors are often ignored in a biomedical system. I became curious about what it means to be a woman with a reproductive body and how women make meaning of the experience of pregnancy and maternal illness within their social context. As such, a feminist analysis allowed me to explore the dialectic between the

private/personal sphere and the public/social spheres of women's experiences of maternal mental illness.

I was mindful of my role as a feminist researcher both during the interview and data analysis process. However, at times I struggled with my role as a researcher being more familiar with the role of counselling graduate student. I attempted to build rapport, trust, and respect from the onset of the interview while being sensitive to the needs and comfort level of each participant. I focused on and actively listened to the women's stories to get a sense of their lived experience. I engaged in reflexivity by keeping notes on impressions, observations, reflections, and conceptualizations, as well as my biases and assumptions throughout the research process. I saw my role of researcher as a collaborator in the interactive process between researcher and participant, and by accepting and affirming each participant individually. I was mindful of power imbalances existing between us. I needed to acknowledge my own position as a white, middle-class woman, wife, and mother of four sons who experienced maternal mental illness with increasing severity and intensity with each pregnancy along with feelings of fear, shame, blame and guilt. The experiences of stigmatization, often in my encounters with other health care professionals had a significant impact on my ability and willingness to seek help. Hence, I could empathize with the participants, which helped me build rapport and sensitivity to their experiences. However, I also attempted to *bracket* this by intentionally setting aside my preconceptions, assumptions, and potential biases and by staying close to the data in order to best represent the women's stories, views, and voices.

An interpretive descriptive approach allowed me to take advantage of my interdisciplinarity and aligned with my feminist epistemological orientation, the purpose of the research, research question, and the use of interviews to explore the bio-psycho-social

implications of stigma and maternal mental illness, in a clinical practice setting and in the context of women's lived experience.

### **Participant Selection**

For this study, the sampling was purposeful. Purposive sampling is based on selecting participants with the specific knowledge and/or experience of the clinical phenomenon being studied (Thorne, 2008). This provides information-rich cases that offer an opportunity for in-depth exploration of the central issues. The purpose of this study was to explore women's lived experience of maternal mental illness (clinical phenomena), the role of stigma (socio-cultural context), and accessing mental health care services (specific clinical population).

Participants were recruited from a pool of 120 women who accessed mental health care between 2006 and 2009. All the participants were initially contacted by phone at which point the purpose of the study was explained and they had an opportunity to ask questions regarding the research process and the nature of the study. Once the women consented to participate in the study, arrangements were made for a time and place to conduct the interview for the convenience and comfort of the participant.

The interviews were conducted within a three-week period and then the audiotapes were transcribed by a professional transcriptionist and then coded by myself. In consultation with my committee, we judged that there were sufficiently rich data from the six interviews and recruitment stopped.



## **Data Collection**

Individual interviews provided the primary source of data, supplemented by journal notes, and basic demographic information from intake questionnaires: age, number of pregnancies, number of visits, location seen, and follow-up visits for medication adjustment or counselling. Conducting interviews in qualitative inquiry entails a partnership between the researcher and the participant engaged in the process of making meaning of the experience and information shared. Interviews are designed to delve deeper into the information and/or knowledge about a phenomenon to yield exploratory, descriptively rich and explanatory data (Thorne, 2008). Interviewing participants facilitated a feminist approach as it allowed each woman's unique experience of living with a mental illness to emerge in her voice and through her perspective. This allowed the women to share their experience at a psycho-social level, within a socio-political context, exposing the impact of various aspects of stigma on their experience of maternal mental illness and accessing mental health care services.

With input from committee members, an interview guide was developed, partially based on the literature on maternal mental health and stigma, and accessing mental health care. The guide consisted of a set of semi-structured questions meant to draw out the experiences of each participant. The questions addressed pre-determined areas of exploration within the research topic, such as: a) women's experience of accessing care; b) their understanding and experience of stigma of mental illness; c) how they viewed themselves as mothers needing help for maternal mental illness; d) recommendations they would suggest for services; e) and advice they would suggest for other women dealing with maternal mental illness. No stipend was paid for participation; however, participants were told child care and/or parking would be paid, if required.

At the beginning of the interview each woman signed and was given a copy of the informed consent, although one agreed verbally over the phone, agreed to have audio-taping, and were asked whether they wanted to review the transcript of their interview. Using an interview guide was a way to provide some structure, while maintaining a relatively high degree of flexibility. During the interview, I tried to remain flexible and tolerant of distractions and interruptions. I was mindful of the participant's level of comfort and when she was crying or when a sensitive issue was being shared, I would ask if she wanted to continue or not. This helped build rapport and trust, but also took us off track at times.

At the end of the interview, participants were verbally debriefed and given a debriefing document that outlined the research in general and provided information regarding counselling services and community resources, should they feel the need to further discuss any of the topics raised during the interview or want further support. The form also included phone and email contact information for local services, the researcher and supervisors, and other community supports, in case they had further questions or concerns.

Immediately following each interview, I wrote about my impressions and observations and described the mood and context of the interview, which was the information not captured on tape. These field notes were helpful in providing context and tone of the interview, and for reflection when referred to at times during the analysis process. One interview with each participant was conducted. Although a second interview with participants would have been very useful, especially to allow each woman to clarify and comment on my interpretations, all participants declined to review their transcript and participate in a follow up interview which they stated was due to a lack of time and energy associated with mothering.

## Data Analysis

The analytical process is not only interpretive, iterative, synergistic, and integrative, but also subjective because the instrument for analysis is the researcher who essentially makes all the final decisions and judgments concerning coding, categorizing, decontextualizing, and recontextualizing the data (Starks & Brown Trinidad, 2007; Thorne, 2008). Further, the process of data generation and data analysis in qualitative research is an interactive and dynamic endeavor engaged in throughout the entire research process.

The qualitative data management software, NVivo™ was used in the early phase of the analysis process to manage and initially code the verbatim transcripts. This provided maneuverability for putting data bits into broad-based groupings; however, this did not replace being immersed in the data, nor did it replicate the inductive nature of the analytical process.

According to Morse (1994), all qualitative analyses involve a set of cognitive phases that help depict the intellectual processes by which the raw data are considered, examined and reformulated to become the final research product: decontextualizing, comprehending, synthesizing, theorizing, and recontextualizing (as cited in Thorne, 2000). *Decontextualizing* refers to uncovering and deconstructing the meanings of women's experience of maternal mental illness and stigma which is accomplished by separating the data from the "original context of individual cases and assigns codes to units of meaning in the texts" (Starks et al., 2007, p. 1375).

Initially, the focus of the analysis was on fully *comprehending* each case to develop a sense of the whole, before being combined or aggregated thematically and conceptually, using various layers analysis and angles of perspective. I began by reading each transcript once, to get a general sense of the whole, trying to reflect on my sense of the interview, and each woman's telling of her story. I then reviewed each transcript multiple times, using a detailed, line-by-line

approach, where I assigned a label to each idea or conceptual chunk in each line. The labels were intended as “mental devices” by which information could be sorted, retrieved, and organized - “conveyers of conceptual meaning” (Thorne, 2008, p. 168).

Using NVivo™, I openly coded each transcript, identifying data bits (direct quotations) in each interview assigning broad conceptual labels, which resulted in 52 coded concepts (e.g., advice, barrier, support, concern, media, initiating event, history, stigma, comments from others, health care providers, self-esteem, satisfaction, emotional responses, etc.). Open coding, according to Thorne (2008), involves “fracturing the data – taking it apart and examining those discrete parts for the similarities and differences they reveal” (p. 145). This facilitated the process of decontextualization, but also produced an overwhelming amount of discrete data bits that were then organized into narrower conceptual categories, without regard to context, in order to distinguish similarities, identify redundancies, and begin clustering the data (Kearney, 2001).

To do this, I used post-it notes as a visual aid, each with one of the labeled concepts, and arranged these into narrower categories revolving around common themes or properties, in the form of a conceptual map, providing some logical structure from which to launch further analysis. I worked with the data “from pieces and parts into patterns and relationships” (Thorne, 2008, p. 166). Discrete data bits were aggregated into broad conceptual categories, for example the data chunks aggregated under:

- a) *outcome/impact* - relationships, work/school, and current condition;
- b) *stigma issues* - comments from others, myths of motherhood, IVF, stereotypes, stigma, identification, normalization, labeling, and language;
- c) *treatment* - symptoms, medication, PPD, diagnosis, bipolar, anxiety/depression, compliance, side effects, risk factors, sleep, stress, screening, and fertility drugs;

- d) *other themes* - (i.e., people, contextual factors, elements of care, feelings and attitudes, advice to women, coping strategies, women's background and history, health care providers, contextual factors, emotional responses, and attitudes).

As a means of organizing the raw data chunks pertaining to each conceptual category, I used the software to aggregate these labels and printed a transcript of the raw data (direct quotations) for each conceptual data category. I then read the women's truncated quotes, line-by-line, from the perspective of these conceptual categories, to identify and explore interactions, relationships, and recurring themes, and the conditions and contexts within which they were embedded. This allowed me to refine them into narrower and denser descriptive categories, to distinguish the basic concepts contained within each transcript, to determine what elements characterized those concepts, and then, labeled each descriptive category. For instance, the descriptive categories associated with accessing service were: access, wait time, follow-up, health care providers, other services, health care system, screening, alternative therapies, referring/attending doctors, overall experience/satisfaction. I then used the descriptive categories to discover and openly explore patterns and relationships.

According to Sandelowski and Barroso (2003), descriptions "always depend on the perceptions, inclinations, sensitivities and sensibilities of the describer" (p. 913). Hence, I attempted to be mindful to repeatedly return to the raw data to help distinguish between the women's descriptions and my own, staying as close to the data as possible. In order to accomplish various levels of description and interpretation, several analytical strategies - iterative and inductive process, creative synthesis, and constant comparison-were used to explore, described and interpret the data for this study, which required varying levels of immersion into the details and specifics of the women's experiences within three dimensions.

The inductive and iterative process was sifting and sorting through data chunks to detect, describe, and interpret conceptual categories, search for inconsistencies and contradictions, and generate conclusions about what was happening and why (Thorne, 2000, p. 69). Constant comparative analysis was oriented toward finding commonalities and patterns within the phenomena, while taking into account the social processes that influence behaviour and experience (Thorne, 2000, p. 69). A creative synthesis through analytic processes helped detect the main narrative themes within the accounts the women gave about their lives, and discover how they understood and made sense of their lives (Thorne, 2000, p. 69).

The next level of interpretation was *synthesizing* a portrait of the phenomenon that accounts for relations and linkages within its aspects (Thorne, 2008). For this level of analysis, I explored the descriptive categories in terms of the three dimensions of women's experience: personal experience of living with mental illness; stigma; and accessing mental health care. The goal was integrating concepts into a linked and logical manner, which provided a synthesis of shared meanings and shared experiences as they emerged (Kearney, 2001). To facilitate this, I used a visual aid by constructing tables and matrixes for each dimension, which contained truncated data bits to represent the descriptive content of each woman's experience within each category. This allowed me to explore common instances, frequencies, similarities, and differences in the women's stories which offered a more holistic picture of what it means to live with maternal mental illness and the stigma, and seeking help and accessing care. This allowed the interpretation to go beyond shared meanings and experiences by providing a depiction of experiential variations (Kearney, 2001).

Third phase of analysis was *theorizing* about how and why these relations appear as they do searching for the tacit knowledge which is implicit, hidden from self-consciousness (Audi,

2001). Throughout the analysis, I used various reflective and analytical practices to keep track of my thoughts and ideas as they were evolving, and as I engaged deeply with the data. I challenged myself to not only bracket any preconceptions and assumptions, but also I challenged myself to consider what I might be missing or what alternate interpretation may pertain to what I was seeing (Thorne, 2008). Using visual aids, such as post-it notes, creating tables, matrixes, and mind maps to help me conceptualize and externalize my inductive reasoning and visualize linkages and relationships. Documenting patterns and themes this way allowed me to reconfigure what was found into a form that had potential to shift my angle of vision (Thorne, 2008). Each new relationship, and level of interpretation raised further questions; I repeatedly returned to reading the raw data and jotting down new ways of thinking about it, comparing and contrasting data categories until they no longer continued to give new insights. I would return to the research literature to see whether there was anything within my findings that would offer a different angle of interpretation on any initial impressions and interpretations (Thorne, 2008). This level of interpretation provided dense explanatory descriptions of women's lived experience of maternal mental illness, stigma, and accessing mental health care.

The final phase of analysis, *recontextualization*, “examines codes for patterns and then reintegrates, organizes, and reduces the data around central themes and relationships drawn across all the cases and narratives” (Starks et al., 2007, p. 1375). The core categories provided a recontextualization from which to generate an evolving descriptive understanding and interpretive analysis of the women's experience of mental illness, stigma, and accessing mental health services by putting new knowledge about the phenomenon and relations back into the context of how others have articulated the evolving knowledge (Thorne, 2008).

Thorne (2008) cautioned against potential problems in inductive analysis: premature closure; misinterpreting frequency; and hyper-reflexivity. Due to having to take a leave from my research, for compassionate reasons, having several months distance from the research presented possible challenges with *premature closure*. I had to re-engage my research mindset and analytical process, by re-immersing myself into the data, starting from square-one in order to re-acquaint myself with what I had done previously; however, this also provided the opportunity to getting to know my data, the women's stories, intimately. This slowed down the analysis significantly and extended the time it has taken to complete my master's thesis, which at times made it tempting to rush the process. But rather, it became an active process that allowed me to look at the data from a slightly different perspective, at various times during the research process. I started by re-reading each participant transcript, and then re-creating my train of thinking in developing the emerging concepts, and getting a sense of the whole. I attempted to inductively make sense of relationships by shifting attention from individual cases to the whole; constantly comparing each category to all the other categories to explore similarities, differences and general patterns which allowed me to gradually achieve an increasing the level of clarity and complexity (Kearney, 2001; Thorne, 2000, 2008).

This became a dialectic process of description, interpretation, reflection and affirmation, where the interpretation of each part is dependent on the interpretation of the whole (Audi, 2001). Indeed, it gave new insights into what was emerging from the women's experiences, things that I had missed when I was engrossed in the initial stages of the analysis, immersed in volumes of information, and bogged down by the mechanics of the data management software.

*Misinterpreting the frequency* was minimized by engaging in the numerous steps and deeper layers of good inductive analysis, previously discussed. This helped to identify the



relevance, significance, and/or redundancy, of certain descriptive codes and helped to ensure complexity by identifying the multi-faceted interconnections within women's lived experiences and shared meaning (Kearney, 2001).

*Hyper-reflexivity* occurs when the researcher becomes self-absorbed and has difficulty sorting out their interaction with the participant and the data being shared (Thorne, 2008). These analytical problems were minimized in this study by being fully engaged in the iterative, inductive, and evolving data analysis process which allowed me to come to know the data intimately by being fully immersed in the data at times, while at other times, stepping away to gain some distance to have a fresh look at what was emerging. Interaction with committee members about the analysis also helped with this. I was also mindful, as a feminist researcher, to be a faithful witness to the women's experiences, views, and voices. I did this by bracketing my preconceptions and assumptions attempting to keep an open mind; I also returned to the original interview transcript to check out whether my descriptions or interpretations were a reflection and honest representation of the women's experiences.

The final stages of analysis consisted of determining how to present the findings, thinking about the writing, and striving for an adequate balance between description and interpretation in conceptualizing the findings (Thorne, 2008). This also entailed going back to the literature to check whether new insights were new or simply missed when conducting the initial literature review. Each phase of writing the thesis and implementing suggested revisions, provided another level of analysis, as I was able to identify nuances previously missed, and further refine and condense the presentation of the findings in a more cohesive and accessible manner. This helped to develop an overall organization in which to convincingly present the findings, which allowed me to describe, interpret, and articulate the interconnections of three dimensions of women's

lived experience of living with maternal mental distress, the implications of stigma, and accessing mental health care services.

## **Evaluation Criteria**

All qualitative research methodologies have developed quality criteria to assist with guiding the way in which a study is conducted and findings are presented to the intended audience (Thorne, 2008). These distinct guidelines are used to ensure rigor and credibility and judge the quality of the research process and product (Thorne, 2008). Research quality, for interpretive description, depends on the match between the question, the method, the design, and the researcher's stance, while credibility involves maintaining clarity of purpose (Thorne, 2008). Thorne (2008) delineated four principles for articulating standards of evaluation within interpretive description: a) epistemological integrity; b) representative credibility; c) analytic logic; and d) interpretive authority.

*Epistemological integrity* is assured when the research process reveals a research question that is consistent with the stated epistemological standpoint and interpretation of data and interpretive strategies which follow logically from that question (Thorne, 2008, p. 224). By using a feminist framework to inform the exploration of women's lived experience of maternal mental illness, the social construction of motherhood and pregnancy, and the impact on accessing care, integrity was achieved.

*Representative credibility* was addressed through the research process by being immersed in, and having a prolonged engagement with, the data by using multiples angles of inductive analysis. This was supplemented with notes of observations, impressions of interview and participant, and the context and environment. Interpretations were checked by returning to raw data and individual interviews to confirm that what was being represented was as close to the

women's experience as possible. The women were not representative of all women's experiences of maternal mental illness. This study is but a glimpse.

*Analytic logic* was ensured with the detailed descriptions and interpretive analysis of each interview and each descriptive category to comprehend the women's unique perspective and how they made meaning of their experience of being a mother with a mental illness, in the context of their lives.

*Interpretive authority* was addressed by taking into account and acknowledging my epistemological stance, disciplinary background, and personal experience and the role this had on the research design, analytic process, and descriptions and interpretations of the findings. However, I strived to bracket any biases and assumptions I had throughout the research process by taking steps to document reflections and observations along the way, and by staying as close to the women's experiences as possible, often going back to the original interview script to confirm my interpretations as being fair witness to the women's stories, views, and opinions.

### **Ethical Considerations and Approval**

The current study received ethical approval from the University of Saskatchewan's Behavioral Research Ethics Board. Participation was strictly voluntary and through the informed consent process, participants were assured confidentiality, anonymity, and the right to withdraw at any point during the study. Participation in the study did not affect access to mental health care services or care providers. The documents, transcripts, and consent forms, are available solely to the researcher and supervisor and will be stored in a secure location for five years.

To ensure confidentiality, pseudonyms were used to protect each woman's identity: Amy, Elyse, Sue, Gabby, Tina, and Skye. Following the interview, participants were provided with a debriefing document that included information regarding counselling services and community

resources in the event of needing to further discuss any topics raised during the interview, or if needing further support. This form also included the researchers' contact information in case they had any questions or concerns.

## CHAPTER 4: FINDINGS

The purpose of this chapter is to describe the findings which reflected women's lived experiences of maternal mental illness and accessing mental health care. Three dimensions of experience are explored: a) life with maternal mental illness; b) aspects of stigma; c) and accessing mental health care services. Each of these dimensions are described and interpreted separately not only to bring forth each woman's unique voice and situation, but also to illustrate the shared meaning of living with maternal mental illness within these bio-psycho-social domains of experience. Further, the findings explore the interconnections between living with mental illness, the impact on women's sense of self and the influence of social and self stigma on seeking/accessing mental health care. The chapter concludes by presenting the women's recommendations for enhancing service provision and favorable health outcomes and their advice for other mothers living with mental illness.

To protect confidentiality and anonymity, pseudonyms were used for each participant. Direct quotes ensured that participant voices were central to describing the findings and were *italicized*. Deleted words have been represented by ellipses, and added words are represented by square parenthesis. Each participant was offered the opportunity to review a written transcript of her interview. However, all declined to review their transcript and expressed a lack of time and energy related to being new mothers. Interviews were sixty to ninety minutes in length, except for the one conducted over the phone, which was 30 minutes.

### **Women's Experience of Maternal Mental Illness**

Although the sample was gathered in a relatively random way from a list of attendees, the six participants represented a rather homogeneous group of white, middle-class women living in an Anglo-prairie medium-sized Canadian city who accessed mental health care services. At the

time of accessing services, five of the six participants were 31 to 39 years of age, except for Skye who was 18. Five of the women were married, except Elyse who was divorced from her previous spouse and was living common-law at the time of the interview. Three women had post-secondary education, two of which were health care professionals, two were working in retail, and one was an exercise instructor. Three of the women had a child from prior pregnancy, and of these, two women (Amy and Elyse) experienced postpartum depression (PPD) after their first delivery. They were both treated pharmacologically and discontinued the medication prematurely. Three of the six participants (Sue, Tina, and Gabby) had a history of infertility, and used fertility drugs and in-vitro fertilization (IVF) to conceive, which impacted their experience of mental illness and stigma; Tina and Gabby both had twins as a result. This was quite unusual in a small sample size and revealed interesting findings that added to the richness of the data analysis as this provided the opportunity to explore the bio-psycho-social implications of fertility, the process of IVF and maternal mental health.

**Participants.** Each participant shared her experience of having maternal mental illness, living with and managing emotional and mental distress, and the impact this had on her life and relationships. Although each story was unique, many similarities were noted in their descriptions indicating a shared experience and shared meaning of living with maternal mental illness. This dimension of women's experience coalesced into the following common areas: a) personal and family history of mental illness; b) debilitating symptoms and mental/emotional distress; c) potential contributing factors; d) diagnosis and treatment; e) impact on relationships with spouse, family, co-workers and others; f) impact on their sense of self and effort in seeking help (self-efficacy); and g) their health outcome.

**Amy.** At the time of the interview, Amy (33 years of age), was married and expecting to return to work full-time within a few weeks. Her spouse and two children (ages 4 and-a-half-years and 22 months) were home, but out of earshot, during the interview. When she accessed mental health care, she was 28 weeks gestation and seen once, during her second pregnancy. Of the six participants, Amy's symptoms of mental illness were the most extreme and debilitating, and continued to be an ongoing struggle at interview time. Amy acknowledged having PPD after the birth of her first daughter, for which her first family physician (out-of-province) prescribed a psychotropic medication; however, she discontinued these prematurely due to side effects: *because it was an emotional blocker, I was taken off the medication [six weeks postpartum]. That was it. I wasn't offered any other alternative at that point.* Amy was still experiencing mental and emotional distress at 30 months postpartum, when she became pregnant with her second child. Amy described her emotional state and the escalation of distressing symptoms:

*I was terrified when I found out that I was pregnant the second time, because it was so bad with the first. I was never out of the woods with the first pregnancy, but the second time around, it was exasperated (her words) greatly, and it came to a point where I couldn't live with the thoughts and visions coming into my head, particularly stepping into the kitchen. I couldn't look at knives, and couldn't look at the frying pan. I couldn't go into any room without picturing me hitting her with something.*

Amy acknowledged reaching a felt crisis point before finally going to her family physician for help: *One day I got to the point where I was really frustrated with [my daughter]; it may have been because of lack of sleep. I am not sure. I put on her coat a little too rough and she fell on the ground and hit her head. ... I realized that I just had an absence of concern. It was*

*like I didn't care and that really scared me tremendously because I didn't know at that point if I was a danger to her.*

Although Amy had PPD with her first pregnancy, she had prematurely discontinued medication and seemed ill-informed of her risk for developing PPD with future pregnancies. As a result, she did not seek help until she experienced a crisis point with the second pregnancy. Amy's family physician immediately referred her: *I was at a critical point that is why I went to my doctor. We were coming in desperation. He was very concerned, and immediately took it very seriously.* Due to the severity of the symptoms, her history of PPD, and her risk for developing extreme psychiatric illness, her physician prescribed a small dose of anti-depressant to initiate pharmacological treatment, in the interim to accessing mental health care services. As a result of the relief she was experiencing with the medication when accessing care, Amy recalled being told to continue the medication and to follow-up with her family doctor. She stated that she felt no other treatment options or services were offered. Unfortunately, the relief of her symptoms was short-lived. After being on medication for a short while, Amy recalled:

*I was starting to have problems again. I finally got to the point where I was on higher doses of medication, and I was sitting at the patio window, trying to talk myself out of leaving the house, not leaving my daughter alone in the house. I was just going to leave the house and start walking, and just go. I thought to myself, maybe she needs to be taken away; maybe I need to be hospitalized. I can't live like this anymore. My family doctor was gradually increasing [the meds] because it was starting to come through my dreams, and I was starting to struggle again, so it was gradually being increased to more and more.*



Amy and her spouse had recently moved from another province at that time and had no family support nearby. Amy identified the lack of proximity to family as a significant factor in her experience of mental illness: *we have no support here; there is nowhere to go and no family to help*. In addition, she shared that her family's religious beliefs also contributed to the feeling of isolation and distress:

*My family doesn't believe in any mental conditions and/or disorders. Both sides - my mother's side and my father's. It did stop them from accepting [that I was dealing with mental illness]. Initially, they told me not to believe it because we are religious and the devil was just attacking me.*

Recently, when she and her husband reached out to them for help when they were having marital problems:

*It was great. It was wonderful to get their support. Now, however, they can't deny there is a [mental illness] problem, especially last month when we hit a wall. We didn't know what to do, we were at the end of our rope. ... [Going home] oh my goodness, it saved my marriage. My husband and my marriage are the last things that I have anymore.*

Amy spoke of the significant challenges her family endured, as a result of her unmanaged mental illness. Amy described the impact that her mental illness had on her husband, as she kept calling him home from work, which made it difficult for him at his workplace:

*I was calling him home so many times that it was getting to be of concern at his job. ... I nearly lost my marriage. ... Even up to a month ago, I was asking my husband if we should separate, because I couldn't stand for him and the children to be going through the pain that I was putting them through.*

Amy was very emotional when she described the effects of having a mental illness had on her two children and how her family was significantly impacted:

*I never really had a life with my children as youngsters. I barely even remember - all those years wasted. The children have been suffering. [Now] my daughter screams. My oldest daughter has been having bowel movements in her pants. ... So, we went from a very successful couple with two beautiful children, who are angels, and happy with lots of friends, to nobody, no family around, no finances, no savings, no security, almost no vehicles, maybe no home. Thankfully, we still have our marriage.*

As a result of her struggle with maternal mental illness and the impact this had on her family, Amy stated that she and her husband, with much sadness and disappointment, made a life-altering decision:

*Because of this [mental illness], because we felt that there wasn't medical support, we actually decided not to have any more children, which I would have loved to have a lot of children. I come from a culturally very big, big family, where there are 10-12 children ... so I felt a huge loss that way. I am still trying to deal with that.*

Amy's mental illness had significant impact on her physical health for which she often felt judged:

*I was very athletic - I kayaked, rock climbed, biked, played on the playground, ran - I did everything, every sport possible. But yah, I am 80 lbs. overweight, and people think that you are, you know, being lazy, taking vacations.*

During the interview, Amy shared that she was still experiencing mental and emotional distress, grieving the loss of having more children, feeling the responsibility of being the sole

income-earner; she expressed her concern about returning to work and doubted her ability to manage the stress and anxiety:

*Now, I am back at work and really shouldn't be. I am not sure how long I can last. I am supposed to start in one week. There are huge concerns about that. I am going back full-time. I don't think that I will ever be able to handle stress again. So, I am actually legitimately concerned.*

At the time of the interview, Amy stated that she was not coping well and when asked about finding help she expressed frustration, hopelessness, and helplessness:

*There is absolutely no [mental health care] support. My only relief, which I have been open about, because I just don't care anymore, is that someday I will die and that it will end. And I was told that it will end sooner than that, but I think that they are lying. I can't stop thoughts coming to my head, which are negative. I do two forms of self-mutilation now. I have been struggling with insomnia. So, in this state, I am going back to work.*

In sum, several bio-psycho-social factors seemed to impact Amy's experience of mental illness: previous history of PPD; premature discontinuation of psychotropic medication; under treatment of PPD; lack of information about maternal mental illness; did not recognize symptoms; lack of family support; religious beliefs; lack of community support/resources; and stressful life events. Several psycho-social implications were noted: impact on husband (interference at work, job-loss, financial bankruptcy, and depression), children (behavioural concerns), relationship (decision to not having more children and financial strain), work (fears returning and doubts ability to manage stress), and the impact on herself (lack of physical, emotional, and mental wellbeing, lack of sleep and self-care); ability to mother; and her current mental health problems.

**Elyse.** At the time of the interview, Elyse (36 years of age) had two children (ages 12 and 18 months), was currently living with her common-law partner, and had returned to work full-time. Elyse shared that she had mental health issues as a young adult, but had never been treated pharmacologically or with counselling. She recognized early signs of anxiety and depression stemming from never having dealt with a traumatic rape experienced as a teenager.

Elyse was previously treated for PPD after her first pregnancy: *I went to a psychiatrist, a couple of times after my first.* But, she admitted to stopping the psychotropic medication prematurely, without consulting her physician, because it made her *mentally foggy*. At that time, her mental illness affected her marital relationship, which resulted in divorce, many years prior to receiving care:

*I was actually relieved that her dad and I divorced because he didn't deal with me. It wouldn't have worked anyway, because I was miserable with him. Actually, he kind of made it [PPD] like that was the whole reason.*

When Elyse became pregnant with her second child, she began to experience increasing amounts of excessive stress and anxiety stemming from extreme job-related stress as a result of being transferred, put on the night shift, and having additional responsibilities at work. Elyse experienced a cascade of debilitating symptoms and reached a point where she was no longer able to manage the tasks of day-to-day living, which greatly impacted her work:

*I was good at what I did, but then I couldn't do it and it got to the point where I didn't want to. I couldn't make a decision, you know, what to go where, any little thing. I couldn't decide anything, nothing came naturally, and it got to the point that I couldn't even go to work - I actually stayed in bed an extra five days, after I walked out.*

Similar to Amy, Elyse described reaching a crisis point before finally seeking help. She described her family physician as being very supportive, aware of her history and risk of PPD, and taking her concerns seriously. She expressed how grateful she was that her physician had referred her immediately for mental health care. Elyse admitted that she did not recognize, or associate her current symptoms and state of extreme mental and emotional distress, to her history of PPD with her first child: *I didn't recognize it and I was just lucky that my doctor did.* When she accessed mental health care, she was prescribed medication which provided relief after being adjusted over the course of a few follow-up visits: *It helped after a little while. I wasn't near as anxious and not as much set me off. She [the psychiatrist] had to adjust it a few times during the pregnancy.* Similar to Amy, Elyse stated that she was not offered other treatment options, services and support, such as peer support or a PPD support group, when she accessed care. Further, both participants did not seem to know the implications of taking or discontinuing psychotropic medication and their increased risk for relapse. For instance, Elyse said that she had stopped taking the prescribed medication in the early postpartum (after giving birth) period:

*I came off the medication [on my own] about six months after starting. Just because I felt I didn't need it anymore. I felt that I was kind of over it, it's a phase. It should just kind of clear up by now. I felt fine, and like I said, that was kind of my history.*

As with Amy, Elyse seemed unaware of her risk for developing PPD with her second pregnancy and unaware of the possible consequences of discontinuing medication prematurely, despite being treated twice for PPD. Additionally, both these women described experiencing ongoing mental and emotional distress at the time of the interview, and both were well past the first year postpartum. Elyse (18 months postpartum) shared she was having a difficult time

coping and was very emotional throughout the interview. Elyse acknowledged that she would currently benefit from seeking help and being back on medication:

*I would feel more in control. I wouldn't be as emotional ... you don't have the outbursts and you are not so quick to lose your mind. So, I would rather take the [mental foggiess] over this instability.*

She also seemed to realize that her current inability to manage her stress and anxiety was due, at least in part, to having stopped the medication prematurely. Elyse believed she would be able to cope more effectively with her current condition if she were to use medication. However, she perceived taking medication as also requiring her to engage in the treatment process and being willing to work on life/relationship issues, which she admitted to avoiding. Elyse alluded to having some marital concerns and her daughter's possible behavioural issues:

*[My] daughter doesn't sleep in her crib, so she is with us all night. It was almost like it's my comfort. Part of me doesn't want her to sleep in her own room because maybe then I have to deal with you know - us. Now it is about her.*

Elyse felt supported by her mother and her common-law partner when she was accessing mental health care services, but at times felt isolated from friends because of her hesitancy to share her experience. Elyse's work was also being affected, especially in regards to her relationships with her co-workers and her own high expectations: *Even at work, I'll try to fix everything and it drives me crazy when people make mistakes, but it pisses me right off when I do.*

At the time of the interview, Elyse admitted to not coping well with everything in her life, her work, her relationship, her self-care, and her willingness to seek help:

*I struggle all the time actually, and I know that I am not 100% - not even close. I find that I am moodier because I feel tired. I feel overwhelmed. I worry a lot. I spend extra hours*

*at work, I watch TV, and in a lot of ways, like I am physically there, but I am not, you know, [emotionally present].*

When asked what was holding her back from asking for help now, Elyse had a strong emotional response:

*I don't think I'm ready. It is easier to be unattached - like to go through talking about [our relationship]; to go through having to work at it. Not working at it is easy - it is very easy. It is just - I don't want to work at it.*

In sum, several bio-psycho-social factors impacted Elyse's experience of mental illness: previous history of anxiety/depression in young adulthood (untreated); traumatic experience (rape at age 18); previous history of PPD and premature discontinuation of psychotropic medications; stressful life events (marital problems, previous divorce, and being a single mom); job-related stress; and did not recognize symptoms. Several psycho-social implications were noted: impact on marital relationships; felt supported by mother; daughter with possible behavioural issues; work (over-work, co-workers, and unrealistically high self-expectations; lack of social connections; and the impact on her ability to mother and her present condition (lack of physical, emotional, and mental wellbeing and lack of sleep and self-care) and her current mental health problems.

**Skye.** The youngest participant, Skye (she first accessed maternal mental health care at age 18 and was 20 years of age at interview) was married, working part-time, and had a 24-month-old son. She accessed care in her first trimester and was seen once. Skye revealed not only a personal history of anxiety and bipolar disorders, but also a strong family history of bipolar disorder. She described distressing and debilitating symptoms of anxiety/panic attacks stemming from a phobia of vomiting: *I have a phobia of vomiting, a really, really bad one to the*

*point where it would turn into a panic attack and that doesn't help when you are pregnant and you are nauseous all the time.*

She was diagnosed with bipolar and anxiety disorders as an adolescent, which was managed with a combination of psychotropic medication. Of note, Skye welcomed the diagnosis of bipolar disorder expressing relief and validation:

*I was actually kind of relieved to be honest because I knew that there was something not right. Because I think I was 17 when I got diagnosed, so there is still hormones, and you are still a moody teenager, but I knew that it was beyond what all my friends were going through, so it was kind of nice to know that there was a reason.*

When she became pregnant, her physician expressed concern about the safety of the psychotropic medications Skye was taking for bipolar/anxiety disorder; aware of her risk of developing PPD, she was immediately referred for mental health care by her physician:

*I had to stop all [medication] because they weren't sure what was safe and what wasn't. He put me into top priority because I have a lot of bad anxiety and phobia issues and he wanted to make sure that I got help with the medications, ASAP.*

Skye stated that she was told to continue one psychotropic medication, which was safe to use during pregnancy, and to discontinue the others. However, she said that she was never informed about her risk of relapse, her risk for developing PPD and the implications of taking and discontinuing medication in light of her bipolar disorder. Further, Skye said she was not offered other treatment options, services, or support.

Skye admitted to using the medication for a while during her pregnancy, but explained the negative side effects were hindering her ability to function daily, much like Amy and Elyse who also experienced medication side effects, which influenced their decision to discontinue



taking them. In addition, Skye stated that the medication became too costly; hence, she discontinued them during her pregnancy without consulting a physician:

*[It made me] feel zombie-like. ... It would have helped, if I wasn't so exhausted all the time. The medication, if you don't sleep 16-20 per day, then you feel that you are dying, basically, because you are so tired. And I actually couldn't afford the medication at the time. And I did ok after a while.*

However, unaware of her increased risk of developing PPD, Skye did not recognize her emotional and mental distress after having her baby. In fact, it was Skye's mother who questioned and recognized symptoms of PPD:

*I had a really bad postpartum period. My mother was worried, she had come down to see me because I was emailing her, and she noticed that I wasn't happy. ... My mother realized that it was probably postpartum, so she came to see me and see how we were doing. So, that was good to have someone that close to you who knows exactly what it means.*

Skye spoke of the support and help she received from her husband and mother, which allowed her to manage her symptoms. She attributed this support and understanding, at least in part, to her family member's personal experience with mental illness:

*[My husband] had been amazing and helpful with my anxiety. Actually, he learned a lot of tricks to help me calm down. ... My mother is bipolar and so was my brother, so everyone was there to help me, if I didn't have enough help. My mother went for years, until she was just about 40, without medication, and not really knowing that she had it. And so, she understood me. I probably wouldn't have gotten through a lot of stuff if it hadn't been for her support.*

Skye indicated that although her spouse was very supportive, he did not understand the struggles she was experiencing after she had the baby:

*My husband, he gets some things, but he never really understood the postpartum part, so he never got why I wasn't eating, and even when my son was sleeping, I wasn't sleeping. ... There have been times where my husband has had to wrestle me out of bed, when I was dealing with my lows, as well as having to take care of my son during the day, and I didn't have the energy to cook us a big meal.*

Despite the positive encouragement and support received from close family members, Skye's experience with mental illness had a significant influence on her relationships with extended family, co-workers, and her school administration. Skye described her strained relationship with her paternal grandparents, as a reality of living with mental illness:

*My grandparents, they blamed everything on bipolar, they have really old-fashioned thinking. ... They blame my parents' divorce and the fact that my mother is bipolar. ... If I feel a lull coming on, and I am going to my grandparents, I will put a big smile on my face and say, "I am doing fine" because I don't want to hear their bantering.*

Skye also commented on how she would censor herself in the often awkward and uncomfortable social interactions at her workplace:

*At my job, they knew about my phobia [of vomiting] I would have a little panic attack. So they would need to know that, but they didn't know about me being bipolar or anything.*

Further, Skye's experienced the negative impact of not only having a mental illness, but also for being a pregnant teenager. She explained how she felt about the way her school's administration treated her:

*And the high school that I was going to at the time knew that I had bipolar disorder, because I had to go for a lot of blood tests because of the medication that I was on. When the school found out that I was pregnant, they told me that maybe their school wasn't right for me anymore. So, I went to a different one. ... I honestly think that it was because they were uncomfortable, because I explained to the principal that I had bipolar disorder and ... then when they found out that I was pregnant, they used the students as an excuse, saying that, "they would never welcome me." But I could tell that it was the counsellor saying that, and the principal came in, as did the vice-principal. It was obvious that they didn't want me there - the way that they were trying to blame it on the students, but there is other pregnant people there. They would have been fine with it. So, I left that school. It kind of worked best because I had ridiculously understanding teachers [at the new school], and some of the teachers there were influential to me, in the end, because they had really good advice on life and childrearing.*

Skye's sense of ambivalence revealed that she had made meaning of this experience by choosing to see the positive and not allowing negative social encounters to diminish her sense of self. This seemed to be a protective factor in her experience and seemed linked to her sense of self-efficacy. Unlike Amy and Elyse, Skye who was also at increased risk of developing PPD, stated that she was currently doing well, without psychotropic medication. Skye proudly explained how *I basically did it myself* and that she learned effective strategies to manage her mood disorder by learning effective coping strategies and gaining more self-awareness:

*Actually, I was off medication since before I delivered. I have been doing really well. I have learned to tell when things are coming, you know? With the irritability, I have learned to basically control for the most part, except for the PMS - that kind of adds to*

*everything - that is pretty bad. But with the lows, I have learned to completely control them now.*

In sum, several bio-psycho-social factors influenced Skye's experience of maternal mental illness: previous history of anxiety and bipolar disorders; under treatment of mental illness; family history of mental illness; stressful life events (teen pregnancy and asked to change schools); discontinuation of psychotropic medication; and a lack of awareness of symptoms and risk of PPD. Several psycho-social implications were noted: impact on her school life; impact on relationships with spouse, mother, students, co-workers, and extended family; impact on her sense of self (learned new skills and sense of wellbeing).

**Sue.** At the time of the interview, Sue (39 years of age), was six months postpartum, married with one child, and on maternity leave. The interview was conducted at her home, and her 6-month-old daughter was awake, and she held her for the duration of the interview. Sue was the only participant who participated in a support group for postpartum depression.

Sue, one of three participants who used *in-vitro fertilization* (IVF) to conceive; she had had numerous miscarriages and had experienced mental and emotional distress with each. She had a history of anxiety (untreated), beginning in her 20s, with her first miscarriage. When she finally conceived in her late thirties, and after a few years of IVF treatment, she began to experience extreme anxiety. She recalled going to her obstetrician, who was aware of her risk for developing PPD, and referred her in the last few weeks of pregnancy: *my doctor mentioned [service provider] when I was pregnant. They were concerned because I had a lot of anxiety and they were concerned about me being depressed after.*

Sue delivered her daughter three and a half weeks early and recalled the details of a traumatic labour and delivery and the heightened emotional distress this caused:

*Her heart stopped before she was born, and I was convinced that she was dead. They used forceps because we couldn't wait for me to push, and I saw there were a whole bunch of nurses and doctors. Two doctors stayed to do the stitches and everybody else had gone around her. My husband couldn't even see her. They didn't tell us her gender. I had to finally ask after a few minutes, and then she cried once, and I thought, yah. And then she stopped. I was convinced that she was dead, and then she cried again, but then stopped again. By then, I had just kind of resigned myself to the fact that she was going to die. ... And then after [labour and delivery], you are totally exhausted and messed up. So, it was horrible and for the next three weeks, I was convinced that she was going to die. I think it took 3 weeks to relax a bit, but it was not until she was 5 months that I was able to really relax. Now, I would say that the last two months have been really good.*

Sue was the only participant who had never used psychotropic medication. Rather, she preferred a more holistic approach, using alternative therapies: *I was on non-prescription medication. I have an acupuncturist who does traditional Chinese medicine and he had given me a bunch of stuff to prevent a miscarriage, and so I was taking the stuff he gave me.* However, her struggles with infertility and anxiety had an impact on her relationships—with her spouse, her in-laws, and co-workers:

*It sure 'highlights' the weaknesses in your life. Like, if you have a weakness in your relationship, it just makes it "scream" and that kind of thing. ... It is hard to get any information out of my husband, at the best of times, let alone something personal.*

Although she felt supported at times by her family, she was disappointed with her mother-in-law for betraying her confidence: *when my sister-in-law found out I was pregnant. I didn't tell her; my husband didn't tell her. So, I am guessing my mother-in-law told her, which*

*disappointed me.* In her interactions with co-workers, Sue was reticent to discuss her pregnancy using IVF, which caused her to feel isolated. She mentioned how co-workers would ask inappropriate questions: *I didn't want my co-workers to know because I work with a lot of people who are harsh and judgmental - most of them.* Sue, however, felt supported at times, when attending the PPD support group with other women, but yet at other times, she felt alienated: *it was nice to see other women having similar feelings, anxiety, all that kind of stuff, but at the same time, it was kind of isolating because some of them were really judgmental.* At the time of the interview, Sue was six months postpartum, doing very well, and was managing her symptoms of anxiety.

In sum, several bio-psycho-social factors affected Sue's experience of maternal mental illness: previous history of anxiety; history of miscarriages; using fertility drugs and IVF over several years to conceive; perceived supports; and stressful event (traumatic labour and delivery). Several psycho-social implications were noted: impact on marital and family relationships; impact on social interactions; feelings of isolation; and successful management of her anxiety symptoms without medication using a holistic approach.

**Tina.** At the time of the interview, Tina, 35 years of age, was married and had three children (a preschooler and twins under 6 months. She requested to be interviewed over the telephone and at the start of the interview she informed me that she was breastfeeding her twins, who were born seven weeks premature. Although the interview was shorter in length, in comparison to the others, it contained enough information to include in this study. Tina had a personal history of anxiety that was treated successfully with medication.

Like Sue, Tina spoke of the challenges of using IVF to conceive and attributed her symptoms to her problems of infertility and the lengthy process; but, more specifically, to discovering she was having twins:

*[IVF] was the hardest thing that I have ever gone through in my life, and [IVF treatments] went on for a period of three years or so. ... I started having some anxiety issues, shortly after I got pregnant, pretty much immediately. And I think it was triggered by the fact that I found out immediately that I was expecting twins. I had a four-year-old daughter.*

Tina's physician took her symptoms of anxiety seriously, aware of her risk of developing PPD, and referred her for mental health care. She was prescribed medication *and that helped immediately*. Tina delivered her twins prematurely, which provided significant challenges for her. However, when asked how she felt being on medication during her pregnancy, Tina had some hesitation about the potential side effects, and how she overcame the worry:

*I felt completely crazy and unable to function without it. So, I just decided that I was better off taking the meds and taking whatever risks there might be. I was informed [of potential side effects], but my own personal opinion is that the true effects aren't known at this time. So, I took whatever I was told with 'a grain of salt' because I actually don't believe that the effects will be long-term. ... I just decided not to worry about it.*

According to Tina, taking medication allowed her to cope effectively with her anxiety and her sense of ambivalence about taking psychotropic medication, the possible risk, and managing her symptoms, she made a conscious choice to not let affect her. She was coping well with medication at the time of the interview, and also acknowledged having a good system of support:

*We have a family history of anxiety, so they were just extremely supportive and said that I should do whatever it took to feel better, and the friends that I have shared it with have been equally supportive.*

This echoed Skye's experience, reflecting a shared meaning and understanding of a positive conceptualization of having a family history of mood disorders. This had a significant impact on their sense of being supported through the struggle of living with maternal mental illness, seeking help, and accessing mental health care services.

In sum, several bio-psycho-social factors affected Tina's experience of maternal mental health problems: personal history of anxiety; family history of anxiety; using fertility drugs and IVF; multiple birth (twins) and premature birth; stressful life events. In addition, several psycho-social implications were noted: taking medication when pregnant; impact on relationships, support system, and sense of self.

**Gabby.** At the time of the interview, Gabby (31 years of age) was married, had twin toddlers, and was working part-time. The interview was conducted in the research office. Gabby, the third participant who conceived using IVF, recognized the impact her struggle with infertility, taking fertility drugs, and having numerous miscarriages, had on her experience of maternal mental distress:

*IVF is a whole other area of major anxiety. My husband and I had trouble getting pregnant, so when I got pregnant, I was very scared that I would miscarry and how I would handle that, if that were to happen. I was kind of scared that I would fall into a depression. Infertility was a big issue. I went to see her right away after my positive pregnancy test because I felt that my period was coming and I was just like, "I think that*



*I am pregnant, but if I am not I am going to be devastated. I know that I am going to be devastated.” We had used fertility drugs, too. So, that added even more pressure.*

Gabby’s physician had referred her for mental health care quite early in her pregnancy, aware of her history of anxiety and an eating disorder, her mounting antenatal anxiety, and her risk of developing PPD. Gabby’s awareness of her risk of developing PPD was due, at least in part, to information her husband accessed: *My husband had seen a presentation on PPD. And I thought, “What if that all happens?” So, it was good to go [for mental health care].* Gabby was pregnant, at the time of referral, and was prescribed medication to manage her mental illness. However, Gabby decided to avoid taking the medication, during her pregnancy, due to concerns:

*I didn’t want to fill [the prescription] because ... I was worried about side-effects - weight gain, diabetes, etc., and didn’t want to take it. ... Well, I didn’t go on it when I was pregnant. I went on it after, but I really didn’t want to be on it when I was pregnant. And I don’t have a problem with pregnant women [being on meds] - it is very engrained, “Healthy mom; health baby.” I was so afraid that if I was one of those people who did end up with a defect that could have been completely normal, I would totally blame myself if anything happened and I didn’t want to do that, so I just avoided that.*

Interestingly, Gabby was a health care professional, yet she chose to avoid taking the prescribed psychotropic medication during her pregnancy, which seemed to illustrate a common concern expressed by many people (i.e., safety of medication use in pregnancy). Like Tina, she was ambivalent about taking medication herself and chose to not take medication during her pregnancy, but saw the benefit that other mothers could have from medication.

Gabby acknowledged a history of an eating disorder during her adolescence and of taking medication for her long-time struggles with anxiety:

*I started them when I was 20, and then I got healthy on them. It was horrible coming off them, because of the withdrawal. Then in university, I went back on them, and then went off them again. I had a big change after leaving university and moved to a new city, and started a new job, so I went back on them again. Then, when we wanted to get pregnant, I went off of them, and that was three years trying to get pregnant that I was off them, and then I was on them again pretty much thereafter.*

Gabby's symptoms of anxiety were becoming increasingly problematic in postpartum, yet she seemed to minimize her symptoms of distress:

*I know that after I had the babies [twins] and I had gone to one appointment at my family doctor's, I couldn't stop crying through the whole thing. And they were like, "Oh, go back to see the psychiatrist," and they put me on anti-depressants. ... I thought they were just catching me on a bad day.*

Although she was aware of her risk for developing PPD, Gabby did not associate the mental and emotional distress she was experiencing in postpartum as possible risk factors for developing PPD. This was also the case for Elyse, Skye, and Amy, who all seemed to lack the knowledge of, the foresight, and the awareness of symptoms to associate PPD. Gabby described the psycho-social impact of her mental health problems, and the challenges of parenting twins, had on her spouse and their relationship:

*After my kids were one year, my husband was having depression problems and I was very upset and was trying to contact [care provider]. ... To help me deal with him. ... I thought that I needed to know how to handle this. ... He had problems with depression before too. And then all of a sudden bang - twins - and you aren't sleeping and with your career*

*choices, you are trapped. You feel that you can't start over now because you have dependents ... and kids don't let you mope - you have to play and keep going.*

Gabby described the additional support she received from women in her neighborhood:

*The moms in my neighbourhood, we got together and it was really good because we did talk [some of the challenges of being a mom]. I am maybe a bit shy because I never want to join groups, etc. So, I was very lucky that the women in my neighbourhood contacted me and got me involved. ... I think if I didn't have that, I think that it would be isolating.*

At the time of the interview, Gabby acknowledged that she was working part-time and effectively managing her anxiety with medication and seemed to have a positive sense of ambivalence:

*I kind of like how I feel now, so I am just not anxious about getting off of them, but it may come to that eventually. ... Right at this point, I feel the balance of it. ... And I guess the long-term effects I am not concerned about because you read about the long-term effect of being depressed as well.*

Several bio-psycho-social factors contributed to Gabby's experience of maternal mental illness: personal history of anxiety and eating disorder; using fertility drugs and IVF; multiple birth and miscarriages; stressful life events; lack of awareness of symptoms; lack of knowledge of medication. Several psycho-social implications were noted: impact on spouse (depression); impact on relationships and social interactions; impact on sense of self (to discussed later); and supports.

In summary, several bio-psycho-social factors were identified across participants' experience of maternal mental illness. All the participants had a previous history of mental illness, for which some were treated. Amy and Elyse had previous history of PPD and premature

discontinuation of medication; they also seemed unaware of the risk for developing PPD with subsequent pregnancies and the implications of medication compliance. Both these women had delayed seeking care, during their second pregnancy, until they reached a crisis point. Tina and Skye had a family history of mental illness, which facilitated the level of support they received. All the participants reported experiencing stressful life events and/or interventions for various reasons such as trauma, divorce, miscarriages, and infertility issues. All of the women presented with antenatal anxiety, yet most of the women seemed unaware, did not recognize, or lacked the insight regarding the signs, symptoms, and implications of maternal mental illness. They recalled a lack of information, knowledge, and psycho-education about maternal mental illness, and treatment options; and subsequently, three women discontinued medication without consulting their physician.

Several psycho-social implications emerged from women's experiences of maternal mental illness. All of the women indicated that the level of support they received was a significant factor in their experience. Although some spoke of supportive family and friends, for others it was the perceived lack of family support, social connection, and/or lack of community resources/support that affected their ability to cope with their mental illness. Although the impact manifested in varying ways, all the women perceived having a mental illness as impacting their relationships and various social interactions with their spouse, family members, friends, and co-workers.

Of note, two spouses were described as becoming depressed one-year postpartum, which proved to have a significant effect on the women's experience of mental illness. According to Amy and Elyse, the chronicity of their maternal mental health problems impacted their marital relationships, their children's behaviour, their level of self-care and self-esteem; and for one of

these women, this lead to financial hardship and the life-altering decision to undergo medical sterilization.

For three of the six participants, the potential side effects of using psychotropic medication during pregnancy were a concern. Five of the women were prescribed safe medication, as a result of accessing mental health care; however, three discontinued use a few months after taking them, without consulting their physician and without the knowledge of the implications and risk for developing PPD. At the time of the interview, Tina and Gabby were still on the medication; Amy and Elyse were off medication and described struggling with ongoing symptoms of anxiety and depression; and Sue and Skye described coping well without medication.

An interesting and an unexpected revelation was that three of six participants shared the experience of in-vitro fertilization. Three women had a history of infertility, using fertility drugs and went through approximately three-year process of IVF, which they described as their most difficult life challenge. Further, two had birth complications; and two had multiple births. These three women acknowledged this process as a key factor in their experience of maternal mental illness. Yet, when reviewing an array of scholarly research for this study neither infertility nor the use of IVF, were identified as a risk for developing maternal mental illness. The present study's findings suggested that the areas of reproduction and infertility are significant psycho-social factors for maternal mental illness and linked to self stigma.

### **Women's Experience of Accessing Mental Health Care**

The second dimension explored was the women's lived experience of accessing mental health care services. Each participant spoke about her treatment experience, care satisfaction, and health outcome. The importance of information and the value of the bio-psycho-social approach

emerged from the participants' shared experience and shared meaning of having a maternal mental illness, seeking help, and accessing mental health care. Participants shared their advice for other women who struggle with mental illness.

**Aspects of accessing care.** At the time of accessing mental health care, most of the participants described a sense of being in crisis, having reached a critical point, and for some, a perceived dire need of help. The majority of the women described waiting for their first appointment as too long and feeling like an eternity, regardless of whether they received mental health care within a few weeks or a few months. Amy and Elyse delayed seeking help until their symptoms were extreme, despite having a history of PPD, for which they were previously treated. Neither woman seemed well informed and lacked the insight about their risk of developing PPD, which had a significant impact on their experience of maternal mental illness during their second pregnancy.

For Sue, there was no wait time and access to mental health care *was available right away*. Sue was seen once at 34 weeks gestation, was not prescribed any medication (she was emphatic about not taking any medication), but was to have a few follow-up appointments. She delivered her baby three-and-a-half weeks premature, so she never returned to the service provider. Although she indicated that the early postpartum period was difficult, Sue felt fine with her care: *They didn't think that I needed drugs, and it sounded like they (service provider) really didn't need to see me again*. Rather, a few weeks after delivery, Sue attended a few sessions of a support group for postpartum women; however, she stopped attending the group because she said she felt judged.

Although Tina was seen in a timely fashion, she expressed how difficult it was to wait for the first appointment:

*It took what seemed like a long time; because I sort of felt that I was in a state of crisis - it might have been only 2 weeks, but it felt like a long time. ... Well, initially before I was on meds, I really did feel that I was in a state of crisis, and coping day-to-day felt impossible, so waiting any period of time for an appointment felt like an eternity.*

Tina stated: *in my case, I started meds, and that helped immediately. If that had not been the case, once per month would not have been enough.*

Similarly, wait time was not an issue for Gabby, and she was grateful for being seen early in her pregnancy. Notably, one year postpartum, Gabby attempted to gain information and/or advice about mental health services and resources to help her deal with her spouse who had become depressed. She was frustrated with the how difficult it was to access care and/or other community resources: *I needed to know how to handle this.*

Elyse remarked that she had to wait about two months for an appointment to access mental health care, which she felt was too long to wait. She was prescribed medication that helped after a little while and she was followed a few more times because the medication had to be adjusted a few times during the pregnancy. She continued follow-up with her family physician. At the time of the interview, Elyse was 18 months postpartum, and she admitted to be struggling with a relapse. She attempted to gain access to her physician, when she felt she needed help the most, but it was not an easy feat. Elyse expressed a sense of hopelessness and frustration at being unable to access care, in a timely fashion:

*Like a couple of months ago, I was not doing well for three days, and I went to see my family doctor, but couldn't get in (crying). That just makes you mad. ... and I know that I am not 100% - not even close, but I guess that I got it into my head that [I could] get back in , you just have to say something, and you could get help again. ... So, I did get an*

*appointment. I think it was not until a month later, and I was off by a day. It was actually a Tuesday, but it was supposed to be a Monday, so I didn't bother to rebook and ... it was kind of like, well screw them, forget it.*

Elyse's experience illustrated the effort required to seek help and access care when in a crisis and despair. The end result seemed to be a why-try-attitude, which was a significant barrier to pursuing help for her current symptoms of anxiety and depression. Amy described similar challenges re-accessing care, which seemed to contribute to her current mental and emotional distress and seemed to impact her sense of self-efficacy:

*At that point, I think that everyone just quit trying. I did call every phone number, as well the nurse, the office, the hotline, mental health services, every single psychologist and psychiatrist in the phone book, and everyone kept giving me more numbers to call. I finally quit.*

Because Amy was a health care professional, she further questioned her own ability:

*I say to myself, as an educated medical professional, how on earth did this happen to me? I was calling every number, going to the ER, going to my doctor, telling my husband everything, and he called in to say, "We need help! How on earth did this happen?"*

In sum, all the women during their pregnancy received mental health care quickly because their primary health care providers recognized their symptoms of antenatal anxiety and were aware of their risk of developing PPD and the need to access mental health care in a timely manner. Nevertheless, several the women described the waiting as being extremely difficult due to their distressing symptoms. Amy and Elyse who had a previous episode of PPD, delayed seeking help and accessing care in part due to a lack of knowledge and insight of their risk of



developing PPD with a second pregnancy. Although the initial access to mental health care was not an issue for the participants, trying to re-access care at a critical time was a significant concern for Amy and Elyse. Further, the perceived dismissive attitude of some health care providers was a barrier for Amy in accessing timely and appropriate care, which impacted her ongoing struggle with mental illness.

On the other hand, many of the women in this study described their relationship with their primary health care providers as a vital and positive factor in their experience with mental illness and accessing care. All indicated that their physician took their concerns seriously, took immediate action and referred them for mental health care services, and provided ongoing support.

Gabby's family physician recognized her risk of maternal mental illness: *It was good for me to have that safety net there so quickly.* Similarly, Skye praised her family physician: *my family doctor is probably one of the most amazing doctors. He basically turned into a counsellor half the time.* Although Skye was ambivalent about the various experiences of getting help from health care professionals for her mental illness, she acknowledged the importance of having a positive connection with a mental health provider; that this was a key factor for therapeutic success:

*I think that a lot of it was after you found the one person that you are really comfortable with, it is really hard to find that same person again. ... I had an amazing counsellor, who helped me. ... I went to a couple of other counsellors, but I wasn't as comfortable as I was with her.*

In sum, the women's experiences illuminated several bio-psycho-social aspects of gaining access to mental health care services. All of the women's primary care providers recognized their symptoms and risk of maternal mental illness and referred them immediately for mental health care. The women felt supported and validated by their physician, which indicated the importance of the relationship women have with their primary health care providers. Although, the primary care providers continued the follow-up care, some were uncomfortable adjusting women's psychotropic medication, especially during pregnancy. The effort and difficulty of gaining access/re-access to mental health care seemed to influence their depth of self stigma and their sense of self-efficacy, which seemed to contribute to their current condition and ongoing symptoms of anxiety and depression.

***Care satisfaction and outcome.*** Participants were asked about their satisfaction with accessing mental health care and about the care they received. Sue described her experience as being both positive and negative and seemed ambivalent. She said: *it was more of a "tell us your history" and that was it. So, there wasn't - other than talking about it - there wasn't really anything [that was helpful other than the support group].* Although on the one hand, the support group helped her realize that other women had similar experiences, on the other hand, she felt some of the women were judgmental.

Tina also seemed ambivalent about accessing mental health care although she found relief with the medication: *I didn't find the therapy particularly helpful, at all. I felt that I was disclosing a lot of information and wasn't getting any feedback, or anything to help me. And then again, I responded very quickly to the meds, and at that point, I didn't really feel that I needed anything else. I felt quite normal.*

On the other hand, Gabby's experience of accessing mental health care was described as helpful: *it was good, and it was just nice to talk. I find that I learned something anyways. Like it was good to talk about the eating disorder again and to talk about the issues I had with infertility, because that was a big issue.* Gabby recognized that it was good that the doctor had caught the PPD and referred her for mental health care: *It was good that they caught it so soon, because what a waste to have gone through that. That year was hard enough - we had twins and it was hard enough and to feel the way that I was feeling.* However, she expressed that although she was currently managing her anxiety with medication, she felt tied down by the health care system: *I feel like I start to feel frustrated that I am so tied to the health system, when I have to go to get a prescription refilled, and I have to go to my doctor to get prescriptions, so that part I feel annoyed by.*

Elyse delayed seeking help until her symptoms of mental and emotional distress were extreme and she was grateful that her physician had recognized her symptoms and referred her for mental health care. She was seen several times to adjust the medication, during her pregnancy, and she was satisfied with the care. However, Amy and Elyse reported struggling with symptoms twenty-four months postpartum. Skye was the only participant who reported having a previous diagnosis of bipolar/anxiety disorders and was being treated, prior to accessing mental health care services. Skye shared feeling dismissed and being disappointed. Of note, although Skye's experience accessing mental health care was uncomfortable, she chose to frame it in a positive manner, or in a way that suggested that it did not bother her. In other words, she stated that she did not receive any benefit from accessing mental health care, but decided to not let it have a negative impact of her ability to manage her mental health. This seemed to reflect a sense of self-efficacy:

*[Although] the care services really didn't do anything for me, I just kind of moved on when things didn't work out. I didn't really think much of it (laughter). ... It was kind of disappointing, but it wasn't hard because I understood that sometimes [doctors] don't work out the way that you want them to.*

Amy expressed her disappointment and frustration that she was not provided feedback:

*The interview had very general questions. ... I felt that there were questions, and there was a lot of talking to me and not asking, and to be honest. ... I never learned about how common it [maternal mental illness] is, how to treat it, how long it lasts for, and what are the conditions may aggravate it. I learned nothing except to ask questions for surveys. Yah, there was nothing that I walked away with. No education whatsoever. We did have specific questions. That was more it. [The health professional] talked because we asked specific questions, but looking back, those questions were not relevant to the bigger picture of wellness. ... Interestingly, no one ever did screen me for psychosis. And I can't say that I wasn't psychotic.*

In sum, the women were able to make sense of their experience of accessing mental health care, in a manner that suggested it contributed, either positively or negatively, to their experience of maternal mental illness. For a few women, a sense of ambivalence seemed to have a protective factor. The lack of helpful information about maternal mental illness and the opportunity to talk about their concerns when accessing mental health care was a factor in four of the participants' overall care satisfaction with their treatment experience. For some women the experience of accessing mental health care services involved aspects of stigmatization.

**Information and research.** Some of the women stressed the importance of obtaining or having access to information about various aspects of maternal mental health, such as signs/symptoms, risk/implications, treatment options, and psycho-educational resources. This was identified as a crucial factor in the management of their condition.

For Amy, the lack of information seemed to be a factor in her sense of self-efficacy and ongoing struggle with mental illness. This was also true for Elyse; the lack of awareness about PPD, her risk, and the implications of treatment engagement contributed to current condition. Moreover, for Amy and her spouse, the impact of not having enough information and/or access to resources and supports resulted in the decision to not have more children which she stated was a great loss.

Gabby mentioned that her husband had seen a presentation on PPD which contributed to their increased awareness of the risk of developing PPD; subsequently, Gabby did not hesitate to access care early in her pregnancy. Yet, she did not recognize the symptoms she was experiencing during her postpartum period as being associated with having PPD. This was also true for Amy, Elyse, and Skye, which suggests the need for spouse and close others to have the information about maternal mental illness, as they are often the ones who can be more aware and vigilant.

Gabby commented on the importance of doing research on maternal mental illness: *It just seems obvious to me that when you are having hormone changes, obviously your moods are going to be greatly affected. Then, you are having major changes as well, which is going to affect your moods. It is an important area of research and you know, you are able to find more information about it and what people go through.* Skye described how she educated herself and searched out information to help her manage her mental illness, without medication; this

empowered her to develop effective strategies and more self-awareness of her fluctuating moods: *I have learned to tell when things are coming.* Her spouse and her mother were also instrumental in being aware of her mental and emotional lability. Skye appeared to be very proactive in gaining a deeper understanding of mental illness by reading and informing herself. This reflected a sense of self-efficacy. Further, she acknowledged that reading about mental illness was instrumental in not only helping her manage and understand her own mood disorder, but that reading was also essential for everyone to engage in, to bring more awareness and understanding of those who suffer with mental illness:

*I just read [about schizophrenia] so that I could talk to [my friend] about her mother and actually know what I was talking about. And the same with bipolar - there is a book called "Manic" - I recommend that bipolar people read it. ... Then you understand the way you feel and why you act the way you do. ... So, anyone who does or doesn't have a mental illness should read it. ... It doesn't scare you anymore. You are willing to ask questions. ... You are able to ask questions about it. ... And it is good to answer the questions because you are helping them to better understand and they don't see you as a threat and they don't see you as weird or crazy. The more questions they ask and you answer, the better they understand what you are going through.*

Although Skye's experience of accessing care did not meet her needs, she acknowledged the importance of promoting public awareness and expressed her desire to contribute to research:

*I think that it kind of puts it out there, what mental illness actually is. ... I so wanted to help with this study, so I filled out the surveys and stuff because it is important studies. ... I felt happy knowing that I was at least helping out [a study], and figuring out this stuff.*

In sum, what emerged as an important aspect of women's experience of maternal mental illness and accessing care was the amount and quality of information/education they received from health care providers in regards to the risks and implications of maternal mental illness (for women, spouse, and family), signs/symptoms, treatment engagement and options, and psycho-educational resources. Although some women were aware of the risk of developing post-partum depression they did not associate it with their symptoms of anxiety; however, their health care provider and/or family member had recognized it. The women's sense of self-efficacy seemed to reflect a range of factors influenced by a lack of information and resources versus having an understanding, knowledge, and information about maternal mental illness.

### **Women's Experience of Stigma**

The previous sections recount some of the bio-psycho-social dimensions the women experienced living with maternal mental illness, accessing mental health care and revealed the multi-faceted factors that impacted many aspects of their day-to-day functioning, their level of emotional and mental distress, and their relationships with their spouses, families, and others. The socio-cultural context in which the women experienced their maternal mental illness provided another dimension of lived experience. Throughout the women's interviews were several illustrations of the ubiquitous nature of social stigma associated with mental illness and the often invisible threads of self stigma, which were intertwined with the unrealistic expectations of joyful motherhood. For some women, stigma was a major factor in their experience of maternal mental and feelings of shame, in their ability to cope and in their willingness to seek help. Table 1 illustrates the themes of shame, vulnerability, and fear that were identified across interviews.

Table 1

*Stigma and Associated Emotions of Shame, Vulnerability, and Fear*

Theme	Select Illustrative Quotes
Shame	<ul style="list-style-type: none"> <li>• <i>And you are just like an outcast, like you got this big bulletin board on your head that says, “I am messed up.”</i></li> <li>• <i>Largely because my own religious beliefs, this stopped me from answering truthfully and also because I know that I should be a certain way, as a mother.</i></li> <li>• <i>I hide a lot of what I was feeling. .... [I would think] just get over yourself. Having been through it, I still feel it that way. Because to me, it is selfish because it is not just about you, it shouldn’t be.</i></li> <li>• <i>You know that [mental illness] is accepted, but at the same time, you are like, “I don’t want to be one of them.”</i></li> <li>• <i>You can’t share with your friends how you are feeling because I would be like, “She should be so grateful. I mean not everybody can have babies, so it is a good thing it happens. They would think, “Women have babies, and it is perfectly normal, and they are fine and great, so why aren’t you?” It was like you were defective; you are not the perfect mom.</i></li> <li>• <i>I had a pharmacist tell me, when I was filling my prescription, “Why do you need this, why can’t you just look at your baby and be happy?”</i></li> <li>• <i>I had a big issue with the fact that I got pregnant on fertility drugs. I felt that it made it not as good and that people were judging me.</i></li> <li>• <i>After I gave birth, in the mom’s group, it took me a long time to just say “we used drugs” because I would just hesitate for a while because I didn’t want to talk about it.... It feels like artificial babies. It is weird.</i></li> <li>• <i>I was telling [the doctor] about [my family history of bipolar disorder], and I looked at her, and she rolled her eyes...</i></li> <li>• <i>It took me awhile to share the fact that we weren’t getting pregnant, because I thought it was a reflection of my marriage - that we didn’t love each other enough, or we weren’t compatible enough to get pregnant.</i></li> <li>• <i>I remember thinking all the other mothers were cooler than me - they don’t want to hang out with me because I won’t fit in with the mom’s group, kind of just really, really bad self-esteem.</i></li> <li>• <i>Being “one of those people” who end up with a defect</i></li> <li>• <i>The big thing that I think is important to know too is that I had never thought that I would be angry at my babies because they are babies and they are completely innocent and they have not done anything wrong, and I was angry at them, and I felt super bad about that. I felt guilty and sad</i></li> <li>• <i>They were going to put me on an anti-depressant, and then on as-needed (an anti-psychotic), which I didn’t want to do, because that goes on my profile, and they will think that I am a crazy person (laughter).</i></li> </ul>



<b>Vulnerability</b>	<ul style="list-style-type: none"> <li>• <i>“There may or may not be people behind that glass.” And I was just anxious because I didn’t know that I had a choice to say, “I don’t want all these people,” especially if she was going to ask me really personal questions about you know - depression and suicide and that kind of stuff.</i></li> <li>• <i>We ended you not having any more children because of this problem and this fear. We made decisions that we just probably shouldn’t have and didn’t have to. Why was there not support in that aspect?</i></li> <li>• <i>I went into the ER and I was very visibly pregnant. ... I had told them that I had struggled with postpartum before, I am pregnant now and I cannot handle it anymore and I just wanted to come here to see the doctor. She laughed and said, “That is not going to happen today.” So, I just started to cry and I said that I was told that this person was here and I was sent here, I don’t know what to do anymore.</i></li> <li>• <i>I was at a critical point that is why I went to my doctor. We were coming in desperation.</i></li> <li>• <i>We have no support here; there is nowhere to go and no family to help.</i></li> <li>• <i>There is absolutely no [mental health care] support. My only relief, which I have been open about, because I just don’t care anymore, is that someday I will die and that it will end. And I was told that it will end sooner than that, but I think that they are lying. I can’t stop thoughts coming to my head, which are negative. I do two forms of self-mutilation now. I have been struggling with insomnia. So, in this state, I am going back to work.</i></li> <li>• <i>We have no support here. We weren’t offered any kind of community care access, everybody wouldn’t even look at him, when he had a medical problem. They would just tell him over the phone that he would get better in one more week. ... For a year he suffered from depression. We went bankrupt because of that, so we lost everything, every asset we had.</i></li> <li>• <i>I didn’t recognize it and I was just lucky that my doctor did.</i></li> <li>• <i>I came off the medication [on my own] about six months after starting. Just because I felt I didn’t need it anymore. I felt that I was kind of over it, it’s a phase. It should just kind of clear up by now.</i></li> <li>• <i>So, we went from a very successful couple with beautiful children, who are angels, and happy with lots of friends, to nobody, no family around, no finances, no savings, no security, almost no vehicles, maybe no home. Thankfully, we still have our marriage.</i></li> <li>• <i>And then after [labour and delivery], you are totally exhausted and messed up. So, it was horrible and for the next three weeks, I was convinced that she was going to die. I think it took 3 weeks to relax a bit, but it was not until she was 5 months that I was able to really relax.</i></li> <li>• <i>It might have been only 2 weeks, but it felt like a long time. ... I really did feel that I was in a state of crisis, and coping day-to-day felt impossible, so waiting any period of time for an appointment felt like an eternity.</i></li> </ul>
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<b>Fear / anxiety</b>	<ul style="list-style-type: none"> <li>• <i>I was terrified when I first found out that I was pregnant the second time, because I was so bad with the first.</i></li> <li>• <i>It was horrible. I was convinced she was going to die.</i></li> <li>• <i>I didn't want my co-workers to know because I work with a lot of people who are harsh and judgmental-most of them</i></li> <li>• <i>So when I got pregnant, I was very scared that I would miscarry and how I would handle that, if that were to happen</i></li> <li>• <i>I am scared of going back to work</i></li> <li>• <i>There was always this fear of your children getting taken away if you admit how bad you are. I thought to myself maybe she needs to be taken away. Maybe I need to be hospitalized; I can't live like this anymore.</i></li> <li>• <i>She fell on the ground and hit her head. ... I realized that I just had an absence of concern. It was like I didn't care and that really scared me tremendously because I didn't know at that point if I was a danger to her.</i></li> <li>• <i>I started having some anxiety issues, shortly after I got pregnant, pretty much immediately. And I think it was triggered by the fact that I found out immediately that I was expecting twins. I had a toddler.</i></li> <li>• <i>IVF is a whole other area of major anxiety. My husband and I had trouble getting pregnant, so when I got pregnant, I was very scared that I would miscarry and how I would handle that, if that were to happen. I was kind of scared that I would fall into a depression. Infertility was a big issue. I went to see her right away after my positive pregnancy test because I felt that my period was coming and I was just like, "I think that I am pregnant, but if I am not I am going to be devastated. I know that I am going to be devastated." We had used fertility drugs, too. So, that added even more pressure.</i></li> <li>• <i>"I was so afraid that if I was one of those people who did end up with a defect that could have been completely normal, I would totally blame myself if anything happened and I didn't want to do that, so I just avoided that.</i></li> </ul>
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**Social stigma of mental illness.** When asked to share their views, feelings and experiences of stigma, many similarities were noted in the women's preconceptions and descriptions of stereotypes and of the stigma associated with mental illness and the harmful effects of prejudice and discrimination. Some of the women's views illustrated the pervasive effects of social labels, of being judged, and of the negative psycho-social ramifications of having a mental illness. One of the implications of negative social stigma was being identified with a mental illness, the fear of being labelled "crazy," and having their children taken away, as

a result. Some of the women equated stigma with being marked as “other” and as being less-than. There seemed to be an implied association with being labeled with not only having a mental illness, but specifically with being a “mother” with mental illness, who should somehow be ashamed and feel unworthy of being a woman and a mother. This suggested a deeper level of stigmatization and the underlying social scripts which affect and dictate the everyday lives of women living with maternal mental illness and their sense of self.

All the participants shared the awareness and understanding of the social stereotypes associated with mental illness, the impact this had on all aspects of everyday living and on their relationships and social interactions. Sue identified several common social misconceptions and stereotypes of mental illness:

*From what I have gathered, that if you have mental health issues, you are unworthy, you are scary, you are frightening. It is not worth talking to you because you are going to snap, or rip someone's head off. And if you are pregnant - what were you thinking, getting pregnant and having a baby, because you are so unstable, and you really don't deserve to have kids. ... [Stigma] is labeling someone without knowing all the information, assuming.*

For Amy, stigma was not only a *preconceived idea*, a *preset view*, but also something that impinged on all aspects of life hindering her relationships and social interactions. She alluded to a sense of secrecy, a social taboo of disclosing or discussing mental illness, which fostered feelings of shame, guilt, and isolation. Having a mental illness and belonging to a faith community that denied its existence seemed very difficult for Amy, which was one of the factors that impacted her ability or willingness to share her mental and emotional distress with others:

*[The stigma] oh, at church, at work. It is in so many aspects of your personal life - work life, religious life - it is all the same. You don't talk about it. They don't understand it - people think that you can control it - but you can't.*

Elyse described stigma as being in state of despair and being marked as other - unworthy, which revealed a much more deleterious and insidious aspect of the social stigma of mental illness: *It is a kind of hopelessness and you will always be that way. And you are just like an outcast, like you got this big bulletin board on your head that says, "I am messed up."* This spoke volumes about the psychological implications when social misconceptions become a gauge by which one's character and sense of self is judged.

Skye spoke of society's underlying fear and misunderstanding of mental illness: *"Oh, be careful of her because she might go mad on you," because a lot of people don't understand the disorder. ...Mental illness is not like you are going crazy all over the place and talking to ghosts in the corner.*

For some of the women, the effects of negative social stigma seemed intensified, as a result of their social interactions and the perceived judgmental and discriminatory attitudes and behaviors of others. For instance, Skye perceived the circumstances surrounding being asked to leave/change school as a consequence of being a pregnant, single, teenage mom with bipolar disorder; thus, revealing multiple levels of stigma. Further, she shared an experience, while attending high school, which exemplified the pervasiveness of social stigma and the lack of understanding of and sensitivity toward mental illness, resulting in negative evaluations from others:

*When I was in high school, some of the teachers knew [I was bipolar], but the students didn't. The students openly made fun of bipolar, and stuff like that, and it would be very*

*awkward. Well, there was one case in the news about a woman who burnt down her house and her children in it. And the students were saying, "Well, she probably had bipolar—bipolar people do crazy stuff like that." And I would be feeling uncomfortable, in the corner, because they didn't know. I actually had a teacher in a psychology [class] who one day, said, "Imagine what it would be like to have a bipolar mother and an alcoholic father. That would be awful!" And I was thinking, "That was my life growing up - thanks, buddy!" You feel that they would look at you differently, like you could snap on them at any moment, and I am not like that.*

In addition, Skye's relationship with her grandparents revealed the entrenched nature of negative social images of mental illness: *When [my grandparents] found out that that was going to a psychiatrist - they automatically assumed, "That is good, you are not going to be crazy anymore."* However, Skye was ambivalent, and rather pragmatic, about the social reality of prejudice and discrimination associated with mental illness and the underlying need to be cautious in her social interactions. Skye's sense of ambivalence seemed to have a positive relationship with her sense of self-efficacy:

*When I started working, they would never know [I have bipolar] because even though they legally can't, they can sometimes judge you differently, because of it. Legally, they are not supposed to, but they do. That is just how it is.*

In summary, the participants had a shared meaning and common understanding of the negative stereotypes, and social misconceptions associated with mental illness. Some of the women identified the psycho-social implications experienced as a result social stigma. All of the women had an awareness of the stigma of mental illness, and for some women an identification and internalization of the stigma and shame, which impinges on all aspects of life and social

interactions. Some alluded to a sense of social taboo or secrecy when interacting with others. The women had a shared experience of social stigma, either internally (impact on relationships and sense of self) or externally (the insidious harmful effects of prejudice and discrimination and negative evaluation from others). This highlights the importance of a woman's social-cultural context in gaining a better understanding of and greater sensitivity to her experience of maternal mental illness and the entrenched and often unconscious adherence to the rigid social norms surrounding what it means to be a mother which relates very much to what it means to be a woman.

**Mental illness and the social construction of motherhood.** Participants acknowledged the social norms and expectations of joyful motherhood as a factor in their experience of maternal mental illness and stigma. They spoke of the underlying pressure to conform to the unrealistic and rigid ideals of motherhood through their relationships and in their social interactions. This was often in the form of inappropriate questions and unsolicited advice or comments from others - including health care professionals. This was illustrated in Amy's description of the myth of motherhood:

*Oh, absolutely [there are expectations]. To be happy, to have it together, to be on the scene and vibrant, be at home, or be working. There was a real sense of having to have an achievement greater than motherhood, I suppose. You know just to have it all together. This is supposed to be the best time of your life. ... About being happy - I had a pharmacist tell me, when I was filling my prescription, "Why do you need this, why can't you just look at your baby and be happy?" When I had asked her what these side effects were, so that I could just understand what was going on with my own self - that is what she told me. ...*

As a result of the experience of stigmatization, Amy felt judged, disempowered, and doubted her experience and judgment

Gabby echoed the negative social misconceptions associated maternal mental illness and the use of medication, which illustrated an underlying fear of being labeled, marked, and identified with a socially stigmatized group:

*There are definitely people who don't understand it, and I suppose there may be people who would be choked, if you were on anti-depressants, when you were postpartum, or that you could be 'one of those women who smother their babies.'*

Further, Elyse spoke of the psycho-social implications of the social norms and expectations of motherhood and mothering used not only as the gauge by which others judge mothers, but more specifically a gauge by which women judged themselves and internalized the shame.

***Myth versus reality of motherhood.*** Some of the women spoke of the disconnection between the expectations of joyful motherhood and the realities of the challenges of parenting. To varying degrees, all of the participants seemed to identify with and/or internalized the myth of motherhood; that is, the socio-cultural norms that views mothering as being easy, natural, normal and wonderful, the peak of women's achievements, the greatest joy in a woman's life, and the only reason for a woman's existence

Skye was ambivalent when she acknowledged the reality of being a mother was not always positive and had its challenges:

*I would admit that there have been some times when I was upset when I shouldn't have been (laughter). I am human, children can be annoying sometimes, I am not going to*

*sugar coat that one - sometimes they will look at you and they know that they are doing something wrong, and they will break that thing that you absolutely love right beside you. And of course you are going to lose your cool. ... We are not perfect humans.*

Gabby described an incident at her mom's group when sharing the challenges of mothering, which seemed to exemplify the expectation of being happy mothers and contented wives:

*The moms in my neighborhood, we got together, and it was really good because we did talk about [that]. I remember saying, "I have never been more angry at my husband in my entire life." And, you know, they would just be like, "Yah, me too." That was just completely irrational anger and then I remember thinking, "If he drinks from the milk carton one more time without pouring it in a glass, we are getting divorced."*

For Gabby, being able to share these negative emotions with other women had been beneficial in normalizing her experience and feeling supported.

Sue spoke of how society makes women feel for wanting to have time away from their children, which pointed to a discrepancy between society's parental expectations for men and women:

*When a guy spends an hour per day with his kid, he's a great dad. But, if she wants to have time off, she wants to be away from her kid and then everyone thinks how come you want to be away from your kids?" My life was different before; his life was different before; it has to change.*

Tina also acknowledged the challenges of mothering and needing help with accepting a sense of ambivalence: *a lot of it is difficult, but the difficult times don't last very long, so I try not to dwell on them.*



The women identified and internalized negative socio-cultural messages and scripts of motherhood to varying degrees. Of note, for some participants accepting a sense of ambivalence seemed to be a positive effect on their sense of self, which was also linked to participants' sense of self-efficacy.

***Motherhood and infertility.*** Sue, Tina and Gabby, who conceived using IVF, spoke of their experience with infertility and the process of IVF as a major factor in their experience of the stigma. Each woman had a keen awareness of the negative social stigma surrounding infertility, using fertility drugs and IVF, and multiple births. All had a strong desire to avoid the harmful effects of stigmatization. Further, they had a shared experience of feeling judged and receiving unsolicited comments and intrusive questions from others, which was internalized to a greater or lesser degree.

Sue's thoughts on the stigma surrounding infertility revealed a number of negative social misconceptions of women who have difficulty conceiving, especially the underlying negative evaluation of being an older mother - she was 39 years of age when she delivered:

*A lot of people say, "It's because you are older." It's not like I told people, people don't know, and they comment, "Oh, when you are older, it hurts your chances [of getting pregnant]." "Oh, you are an older mom; therefore you have no eggs. You are going to have a kid with Down's syndrome or another significant disability."*

Tina and Gabby, who had twins, spoke directly of the effects of negative social stigma associated with the use of fertility drugs, and especially with having multiple births, which indicated a shared experience of being judged. Tina expressed her frustration with such inquiries when people noticed her twins: *The number one question they ask is whether they run in the family or fertility drugs. ... But it isn't really something that I wanted to share with people*

*because I don't feel that it is any of their business.* Gabby echoed similar sentiments; however, she went further to point out that feeling judged had a significant impact on her sense of self and her ability to share her experience with others:

*Speaking of stigma issues, I had a big issue with the fact that I got pregnant on fertility drugs. I felt that it made it not as good and that people were judging me. I even had issues when I was working. People would ask me, "Oh, you have twins, was it natural or did you use drugs?" or "Do they run in your family?" and then I just felt instantly judged like there was something wrong with my body, or that I couldn't. ... And then after I gave birth, in the mom's group, it took me a long time to just say "we used drugs" because I would just hesitate for a while because I didn't want to talk about it. So, there is that stigma too. It feels like artificial babies. It is weird.*

This not only made Gabby doubt her experience, but also made her question her own body as she internalized notion that motherhood and reproduction was normal and natural versus artificial and unnatural.

In summary, for the participants having a maternal mental illness was not only about experiencing the stigma associated with mental illness; it was also about how they perceived themselves and how they felt they measured up as women, mothers, and wives.

**Self stigma and maternal mental illness.** The women's experiences revealed certain aspects of self stigma involving the identification with, and the internalization of, the negative social misconceptions associated with being a mother with a mental illness, being unable to cope and needing help, taking psychotropic medication, and using IVF and fertility drugs to conceive. All of the women were keenly aware of existing negative stereotypes of maternal mental illness and the unrealistic expectations of motherhood, some agreeing with and/or applying them to

themselves, to a greater or lesser degree. Participants spoke of the psychological impact of identifying and internalizing various negative aspects of social stigma, that is, self stigma.

For some of the women, self stigma was associated with the fear of being labeled (bad, unfit, crazy), being judged and rejected by others for being a less-than-perfect mother, and for needing help with managing and coping, not only with their maternal mental illness, but also with the challenges of mothering. As a result, this affected their social interactions, willingness to seek help, the degree to which they disclosed their mental illness, their level of treatment engagement and their sense of self-esteem and self-efficacy.

For some of these women, self stigma seemed to be characterized by a sense of self-devaluation: shame, blame, guilt, remorse, feelings of being self-indulgent, feeling like a failure for being unable to handle motherhood, and being defective/weak for needing to take medication. Thus, this demonstrated that at some level, these women identified with and/or internalized the negative social misconceptions and expectations of motherhood, while some anticipated and feared the prejudice and discrimination associated with it, as a result of their personal experience. For some women, self stigma and their diminished sense of self were linked to feelings of shame, which reduced the motivation to seek care and/or continue with the suggested pharmaceutical treatment, and which greatly impacted their self-efficacy, potentially hindering their chances of recovery.

**Factors influencing self stigma.** Self-efficacy emerged as a key psycho-social factor in the women's experience of maternal mental illness and stigma and the treatment outcome— their belief in, confidence about, and sense of personal adequacy in their own ability to manage the various challenges of having a maternal mental illness. Further, self-efficacy seemed linked to a sense of resiliency and feelings of shame, blame, guilt, and ambivalence. Several psycho-social

factors emerged from women's experience of self stigma and sense of self-efficacy, including: the fear of being judged and rejected, the dismissive attitudes of others, the level of disclosure, the meaning of being on medication, and the factors influencing the level of self-efficacy.

***Fear of being labeled, judged, and rejected.*** Some of the participants expressed the fear of being labeled 'crazy', being judged as an unfit mother, and being rejected, as a result of having a maternal mental illness, which impacted how they interacted with their family, friends, co-workers, and most importantly, their health care providers. For some participants, this fear was a barrier in seeking mental health care and influenced their treatment experience. For Elyse, the stigma of having a maternal mental illness meant being marked as less-than-perfect, and therefore, a defective mother, and a label to be avoided: *You know that [mental illness] is accepted, but at the same time, you are like, "I don't want to be one of them."* This led to her fear of being seen as incompetent: *In my job, it would show that I am weak - you know?* Elyse identified with the social expectations of mothers and had internalized feelings of shame, blame, and guilt for being unable to manage her maternal mental illness:

*I can't handle life and my life isn't bad. There is nothing bad about my life. I mean when I was younger, stuff happened, who doesn't have that right? There is always something. ... The self judgment is still there. ... You know logically, you should be happy, you should be grateful. I mean she is perfectly healthy, there is basically nothing wrong.*

Elyse described her reluctance to share her emotional and mental distress for fear of being seen as ungrateful and self-indulgent, causing her to feel isolated:

*You can't share with your friends how you are feeling because I would be like, "She should be so grateful. I mean not everybody can have babies, so it is a good thing it happens. They would think, "Women have babies, and it is perfectly normal, and they are*

*fine and great, so why aren't you?" It was like you were defective; you are not the perfect mom.*

Elyse's fear of being seen as a less-than-perfect mother revealed the impact of internalizing feelings of shame: *Just get over yourself. Having been through it, I still feel it that way. Because to me, it is selfish, because it is not just about you, it shouldn't be.* This emerged as a factor in her ongoing maternal mental health problems, precluding her need for self-care:

*[I am working] full-time and somehow, I find myself trying to do everything, and I know I can't, which is why I am sick right now, because I have worked, I don't know how many days. I will go in on my days off, and I think that I have to do everything now and try to make it all better. (crying) ...I am more understanding of other people's faults and I have almost zero tolerance for my own faults.*

It is also important to note the role that inadequate self-care, lack of sleep, and internalized self stigma and feelings of shame, blame, and guilt, and decreased self-efficacy played in her capacity to cope in the midst of her mental and emotional distress, which seemed ongoing at the time of the interview. This was also the case with Amy.

Amy acknowledged her fear of being labeled and judged had hindered her social interactions with others, for a number of reasons. Amy recognized how her beliefs, both personal and religious, got in the way of getting appropriate mental health care as she was afraid of being labeled crazy by admitting the severity of her mental and emotional distress and extreme psychotic symptoms during her pregnancy:

*And largely because my own religious beliefs, this stopped me from answering [the questionnaire] truthfully, and also because I know that I should be a certain way as a*

*mother. There was always this fear of your children getting taken away, if you admit how bad you are.*

Amy's fear of being labeled and judged was further reinforced by some of her encounters with health care professionals which intensified her experience of self stigma and feelings of shame when accessing mental health care:

*I went into the ER and I was very visibly pregnant. ... I had told them that I had struggled with postpartum before, I am pregnant now and I cannot handle it anymore and I just wanted to come here to see the doctor. She laughed and said, "That is not going to happen today." At triage at [the ER]. So, I just started to cry and I said that I was told that this person was here and I was sent here, I don't know what to do anymore.*

Amy also described an uncomfortable and stigmatizing experience when accessing mental health care

*There was a resident and there was a bunch of people laughing behind the glass. [The health professional] said that there were people observing and I was sitting closest to the glass, and I could hear them laughing, talking, and chatting, and I just thought, "Oh well, this is a joke." ... [That experience] completely reinforced [the stigma]. Apparently, no one took me seriously and no one asked enough questions.*

Amy stated that she felt that some health care providers were dismissive, disrespectful, and unprofessional which was a factor in her reticence in disclosing the full extent and severity of her symptoms. These experiences fostered feelings of shame, vulnerability, fear, and feeling judged, which influenced her treatment experience and her ongoing struggle to manage her mental and emotional distress. During the interview, Amy spoke directly of her mounting

anxiety of returning to work and her fear of being judged or rejected by her co-workers after being on long-term disability, as a result of her severe symptoms:

*I am scared of going back to work - you were talking about perceptions in the public eye.*

*I am nervous to go back to work because of my co-workers. It hasn't been a vacation for me for the past 6 months that I have been off work.*

This seemed to reflect a social misperception of women/mothers living with mental illness who need to take time off work - a stress leave, for example - and the fear of being viewed as self-indulgent or as an indication of being an unfit mother.

Skye also felt judged and dismissed as a result of her interactions with health care providers:

*I was telling [the doctor] about [my family history of bipolar disorder], and I looked at her, and she rolled her eyes, and she went like (facial movement). I felt kind of*

*uncomfortable. Afterwards, I talked about my highs and stuff, and what they are like.*

*And, she basically told me to come back if I wanted to kill myself. Yah, so I was thinking,*

*“Ok, I am not going to come back to you ever” (laughter).*

However, despite the encounter, Skye decided to frame her experience in a positive manner, or in a way that suggested that it did not bother her. This seemed to reflect a sense of self-esteem and self-efficacy. She was ambivalent about her encounter. As previously seen, a sense of ambivalence seemed to be a protective factor in some women's experience of stigmatization.

The fear of being judged for using IVF emerged as a factor influencing three of the six women's experience of self stigma, as well as their self-esteem and self-efficacy in various ways, which revealed the underlying social scripts of motherhood and female reproduction. Gabby

spoke of her struggle with social misconceptions of infertility and the impact it had on her experience of self stigma and her sense of self:

*It took me awhile to share the fact that we weren't getting pregnant, because I thought it was a reflection of my marriage - that we didn't love each other enough, or we weren't compatible enough to get pregnant. The other thing that I felt angry at was my body.*

*And then I just didn't want to share and people would always ask, "Oh, are you guys going to have kids soon?" and I didn't want to share that we weren't. I don't think that I shared it all actually, until I was pregnant, that we had that much trouble. And it was just so painful when people said that they were pregnant and we still weren't.*

Gabby shared how this diminished her sense of self and impeded her social interactions: *I remember thinking all the other mothers were cooler than me - they don't want to hang out with me because I won't fit in with the mom's group, kind of just really, really bad self-esteem.* She shared the dissonance she felt between social expectations of being happy and the reality of her own experience, which fostered feelings of shame, blame, and guilt:

*The big thing that I think is important to know too is that I had never thought that I would be angry at my babies because they are babies and they are completely innocent and they have not done anything wrong, and I was angry at them, and I felt super bad about that. I felt guilty and sad, but think that after talking to the other moms, I felt that it was like a normal thing to feel.*

However, Gabby acknowledged the importance of identifying a shared experience with other mothers as a means of normalizing her negative emotions and self stigma.

The fear of being judged and rejected was also a factor in Sue's experience of stigma in her social interaction when sharing her emotional and mental distress with other mothers in a



support group: *It was kind of isolating because some of them were really judgmental. So anyways, I stopped going at that point.*

The social misconceptions associated with infertility and the use of fertility drugs and IVF was a psycho-social factor in Sue's experience of self stigma and fear of being judged, as a result of inappropriate comments from co-workers:

*[People would ask] just inappropriate questions. You know, I got a lot of stupid comments, even when I was pregnant. ... I told one guy at work because his sister had gone through similar things. ... He was like, "Yah, at least you didn't do like Octomom because she had just had her babies through IVF, and at least you didn't use fertility drugs," and I was like "go away." I wanted to say, "Why would you say that, that is a ridiculous comparison, not every woman is going to say put 6 embryos in and fertility clinics don't even do that in Canada!" But, I had to leave it as a stupid comment and walk away.*

The role of media was also identified by Gabby as a means of promoting women's mental health:

*I think that in the world of Oprah and TV, people are more aware and women tend to go to the doctor more. I think that mental health is something that people are paying more attention to, and I should be more happy in my relationships, and this and that.*

Further, for Elyse, media coverage and celebrity status was identified as important in normalizing her experience of maternal mental illness: *there is a lot of talk about it. There is Brooke Shields - it can happen to whoever. I know that she felt like she was the worst person in the world.*

In sum, the fear of being negatively labeled, judged, and rejected by others was evident in most of the women's experience of self stigma. Some of the participants seemed to have

internalized negative self stigma, fear, shame, blame, and guilt, to a greater degree, greatly impacting their self-efficacy, which was a major stumbling block in their ability to manage and/or seek help for their mental illness. However, other women had a sense of ambivalence about self stigma, some choosing to frame their experience in a positive manner; while others indicated that sharing with other women helped normalize their experience of maternal mental illness and the realities of motherhood, decreasing the negative effects of self stigma.

*Level of disclosure.* Another psycho-social factor that emerged as a significant factor in women's experience of maternal mental illness and the effects of social and self stigma was their level of disclosure. Each participant described the experience of disclosing or sharing with others their mental health concerns, having problems conceiving and taking fertility drugs, and /or having challenges of being a mother. For some of the participants, being in control of certain aspects of their maternal mental illness allowed them to mitigate the harmful effects of social and self stigma - being control of deciding who to tell, or not to tell, or how much to tell.

Some participants spoke of an element of secrecy and feelings of shame and guilt when admitting to withholding information or minimizing their mental distress. Some acknowledged their efforts to hide their mental illness - passing as normal to avoid being stigmatized, judged and/or discriminated against. Elyse felt isolated due to her reluctance to disclose her situation with others for fear of being judged. She also revealed that she would censor herself when seeing her physician.

Similarly, Amy did not disclose her situation with friends and revealed how she was practiced at hiding, and how she took the time and energy to portray to the public that she was normal and competent at handling life and mothering. She also pondered, in retrospect, about whether her efforts at passing hindered her access to appropriate care at a critical time:

*The odd thing is, when things are bad, I actually look good. I do my hair carefully, wear my makeup carefully, because I am trying to put on another persona in order to get myself from A to B. Perhaps, that was why they turned me away in the ER.*

Amy acknowledged how difficult it was for her to share her concerns with others, especially other health care professionals, and that she censored herself:

*Those of us who are in the worst condition don't want it to leave our hearts. Those of us who are in the worst situations are so focused on lying to the public. ... I did have depression before, and I told them outright that it wasn't bad - I did lie. I did go off medication, it didn't go away, and this is a known condition.... I hid the self-mutilation, and I am not proud of that.*

Not fully disclosing the severity of her mental illness seemed to indicate a fear of being judged, which along with feelings of fear, shame, blame and guilt, was a factor in Amy's treatment experience and satisfaction, and health outcome as well as her sense of self-efficacy.

When asked about sharing her situation with others, Sue indicated being selective in disclosing; however she seemed ambivalent about it at times:

*I think that because I have gone to the place where I know that the people who accept it, accept it; the people who don't, won't. I am fine with that. So the people who accept it - I have a pretty good idea of who does and I have a pretty good idea who doesn't. So, if the opportunity came up, and I felt that there was a good reason for it, I might share it with the person who would understand. But, the person who wouldn't understand, I would just leave it. There is no point in going there.*

Sue had selectively disclosed to her family, but became angry and felt disappointed when her mother-in-law betrayed her confidence. Sue expressed the need to be in control of her own experience and information:

*So I told [my mother in-law] and then my sister in-law mentioned it to me one day. She didn't say it in a judgmental way at all, which surprised me also, but I didn't want her to know. I want to pick because it is my ordeal - I want to know who knows.*

Tina also seemed ambivalent about selectively disclosing her situation with family members and some close friends: *I have shared my [mental health] concerns with my close friends and family. I don't feel any sort of stigma from them. It is not something that I would tell a stranger. It is sort of a personal issue.* Interestingly, Tina chose to avoid a situation in which she might have had to disclose the status of her pregnancy when accessing mental health care; she commented on how she did not want to be seen by a family friend, so requested to be seen in the department of psychiatry: *I actually requested not to go to West Winds location because we have family friends that work at the clinic and at that point, I didn't want anybody to know that I was pregnant. It was very early on in the pregnancy.*

Selective disclosure, for Gabby, meant choosing with whom and when to share her feelings and experiences with other mom's in her neighborhood mom's group, although she admitted that it took her a while to feel comfortable to share. She described how sharing her feelings of anger and frustration, via email, was helpful in her feeling less isolated: *I think that email has been very good too because sometimes you can express things in an email that you wouldn't.* Gabby recalled a moment of shared experience, where she felt supported as a result of being able to reveal her feelings and struggles with other moms in her group, which helped normalize and validate her feelings of anger and frustration:

*I emailed one day and I said that "I am going to stuff this way deep down and I wasn't going to tell anybody that I did this - I got so angry today that I threw a glass down and smashed it on the floor." And they all emailed back and they were like "I am so glad you shared."*

Talking to other mothers was definitely beneficial in helping Gabby normalize her experience, increase her sense of connection, thus enabling her to manage her symptoms. This was echoed in Sue's experience of attending a support group for moms with postpartum depression which helped normalize her feelings, on one hand, but on the other hand, she felt judged and rejected for disclosing her feelings, leading her to discontinue attending the group. Similarly, Skye would selectively disclose her mental illness as a way to moderate the negative effects of stigma in social interactions, hence preserving her self-esteem which also indicated self-efficacy:

*There are people who I have learned to reach/not reach out for help - like my grandparents on my dad's side. ... I just don't tell them about how things are. If I am having a rough time, they don't hear about it. I don't need to hear their judgment, especially since they have no idea about anything. If they don't know, they have no right to say a single thing, so I am not going to say a single thing to them.*

In sum, the underlying awareness of the risk of being judged and rejected influenced the level of disclosure, which was a significant factor in women's experience of self stigma and self-efficacy. All the women selectively disclosed as a means of moderating and mitigating the negative effects of self stigma. Some women attempted to pass as 'normal' to be seen as competent, avoided situations to maintain secrecy and/or in which they perceived stigmatization from family, friends, and others.

***Being on medication.*** Another factor influencing women's experience of self stigma and self-efficacy was being on medication and what meaning they made of it. Five of the six participants shared their experience of having a maternal mental illness, being on medication, and the impact this had on their self-esteem. Sue was the only participant who opted to not take psychotropic medication. Three women identified and internalized the negative self stigma of being a mother with mental illness who needed psychotropic medication to cope which was perceived as a failure, or weakness on their part. For a few women, the feelings of shame, blame, and guilt were common emotional experiences associated with maternal mental illness and needing pharmacological treatment.

For Amy, being on medication was associated with the social misconceptions of motherhood: *It is a perception of failure. It is something that's supposed to be natural. ... You feel like a failure in your mind.* Elyse shared this sentiment which illustrated the products of self stigma - a sense of shame and guilt:

*I was not [feeling] very good [about myself]. I was kind of like, "there is something wrong with you, and something doesn't work. It is not normal. You shouldn't have to take medication. Your thinking is a bit twisted. You know logically, you should be happy, you should be grateful.*

However, she had also described the medication as providing relief of her symptoms and helping her cope with mental illness, which seemed to point to some ambivalence. Of note, at the time of the interview, Elyse admitted her reluctance and resistance to seeking further help, or resuming medication, despite feeling extremely stressed and overwhelmed. She avoided seeking help in what seemed to be an effort to convince herself that she could manage without taking medication - being a perfect mother also meant being able to cope. She had previously indicated that her

reluctance to resume medication was also due, at least in part, to her unwillingness to address relationship issues with her spouse. She appeared to struggle with what her perception of taking medication may mean about her, as well as what it may require of her.

Interestingly, both Amy and Elyse had discontinued the prescribed medication without consulting their physician, during their second postpartum period. The rush to be off medication illustrated a shared meaning of the underlying negative self stigma associated with taking psychotropic medication and the strong, if unspoken, desire to avoid the perception of being an incompetent and unfit mother. Further, Amy and Elyse experienced side effects with the medication. This had a significant impact on their self-esteem, self-efficacy, and their current level of functioning.

Gabby acknowledged the negative social stigma associated with maternal mental illness and the use of medication. She opted to avoid taking medication during her pregnancy, despite symptoms, not only to avoid the possibility of adverse effects, but also to avoid self stigma and the shame, blame, and guilt associated with - *being “one of those people” who end up with a defect*. What was interesting was her use of language which unconsciously identified an element of otherness - not wanting to be “one of them.” The need to take medication in postpartum became an issue of self stigma which directly impacted how she felt as a mom who needed help:

*I felt a bit like a failure, just going on medications always does, like you couldn't keep it together. [A perception] I would have on myself [because] you have control of your brain, (laughter), and just that you should just stop thinking of what you are thinking and start to think something else - it is hard to do. I heard stories of other moms with PPD and so I was glad that I didn't get that far. But, I don't know, I felt bad about myself.*

This indicated an internalization of negative aspects of self stigma associated with maternal mental illness which increased the feelings of shame, blame and guilt, which had a significant impact her self-esteem. What was interesting about these comments was the fact that Gabby had stated, a couple of times in the interview, that she had no shame about mental health issues and denied fearing outside opinion, because of having gone through it. However, when sharing her experiences Gabby seemed to have identified and internalized self stigma, one that clearly revolved around taking psychotropic medication:

*I almost felt like I had almost a good reason to be on an anti-depressant, like finally somebody knows. You know, if a pharmacist fills my prescription and I have babies, they would think, "Yah, she needs that." I don't know, that it wasn't a weakness on my part, that I really needed it, but I can't see that I felt ashamed or that I was going to be labeled.*

Her words seemed to reflect a strong desire to justify the need to use medication (having twins), rather than being perceived as having a *weakness* or being *crazy*. For Gabby, there was a direct contrast between her comments about not being ashamed or worried about being labeled and her seemingly unconscious resistance to taking *crazy drugs*:

*They were going to put me on an anti-depressant, and then on as-needed (an anti-psychotic), which I didn't want to do, because that goes on my profile, and they will think that I am a crazy person (laughter). ... I had the prescription written, and I didn't want to fill it ... and I didn't want to take it. And then I brought it to my pharmacy. I knew what they would be thinking, "That is why she was so grumpy - because she is crazy." (laughter). Because I was so grumpy that they took so long to fill my prescription and*



*then I thought that they would see that I didn't fill it and they would think, "She is not taking her crazy drugs." (laughter).*

What was striking was that Gabby associated certain psychotropic medication with "crazy drugs" which seemed to indicate, for her, that taking certain medications implied a simultaneously membership within the ranks of a stigmatized group - a mother with a mental illness. When asked about the contradiction between her reluctance to take medication, despite her health care training, and it being alright for other mothers to take meds, Gabby recognized the discrepancy:

*Well, obviously I am thinking that way. And I would like to think that I don't, like you know, when I see people coming through on those drugs, but I hope not - among professionals anyways. And then non-professionals wouldn't even know what the medication is for.*

Gabby began taking medication during postpartum and continued to do so at the time of the interview. She seemed to be ambivalent about taking medications; on one hand, she did not want to be identified as "crazy" for taking them, and on the other, she was not anxious to get off of them.

For two women (Tina and Skye), taking medication did not have a negative impact on their sense of self and self-efficacy. Although, Tina had used IVF and was taking medication, since her pregnancy, to help with her symptoms of anxiety, she had not internalized the negative self stigma of being a mom needing to be on medication. But rather, she had a sense of ambivalence about having to take medication, had been treated successfully for anxiety in the past, and had made a conscious choice to not worry about it, which indicated a certain level of self-efficacy, and a lack of internalized shame or guilt: *I am fine with it. I have no issues with it*

*at all. Only because I felt completely crazy and unable to function without it. ... I feel that I am able to cope and being on meds has allowed me to be able to cope, so that is as much as I think about it.* Skye, on the other hand, expressed concern about *not* being on medication for her bipolar disorder, and her ability to be a good mother, since she had stopped taking it during her pregnancy:

*I was kind of nervous, you know, not being on medication and becoming a mother. I was taking every tip that I possible could to make sure that I was ok. I was kind of worried that I wouldn't be able to do it, [motherhood]. ... "What am I doing, should I really be a mother? I can't take care of him, if I can't take care of myself."*

In sum, for some women the self stigma of being on psychotropic medication for maternal mental illness was associated with the fear of being labeled - a crazy and less-than-perfect mother who is unable to cope - which lead to feelings of fear, shame, blame, and guilt. This appeared to be linked to the women's sense of self-efficacy. As a result, some women stopped, avoided, or were ambivalent about taking medication, although they all spoke of the relief of symptoms. Other women indicated that they chose to continue taking medication, as it helped them cope and stay in control of their emotional lability.

***Level of self-efficacy.*** The women's level of self-efficacy was influenced by the negative effects of self and social stigma. Self-efficacy was demonstrated in their ability to cope and manage their maternal mental health problems and in the strategies they used to resist, moderate, and/or mitigate the negative effects of self stigma on their self-esteem (feelings of shame, blame, and guilt) and/or in their social interactions (fear of being judged, rejected, and isolation), which was related to their willingness to seek help, their treatment engagement, and their level of disclosure. Self-efficacy seemed to indicate a sense of resiliency which was influenced by

several factors associated with the women's feelings, actions, reactions, and outcomes related to the experience of having a maternal mental illness and the self stigma surrounding it: perceived sense of control, ability to cope, level of disclosure, depth of self stigmatization, level of support, and information access.

Being in control for participants meant deciding who to tell, and who not to tell, when to tell, and how much to tell, taking medication or not taking medication, and being proactive or not. This impacted the women's level of self-efficacy, to a greater or lesser degree. As previously discussed, all of the women used selective disclosure as a means of being in control of the negative impact of stigmatization; however, for some women the lack of disclosure impeded their treatment satisfaction and outcome, their level of treatment engagement, and their social interactions, which further impeded their sense of self-efficacy.

Being in control for Elyse seemed to mean discontinuing the medication on her own, six months after delivery because she felt that *she did not need it*. However, at the time of the interview, Elyse's level of self-efficacy seemed limited; she seemed to have diminished self-esteem, feelings of being overwhelmed, and was not coping effectively. Elyse also avoided sharing her situation with friends as she feared being judged and rejected, which contributed to feelings of isolation and shame.

Similarly, after prematurely discontinuing the medication, Amy's sense of self-efficacy was limited, due in part, to a fear of being judged and a resistance to seeking help, influenced by her beliefs, her personal experiences of enacted stigma, and the dismissive attitudes from others impacting her self-esteem. For Amy, being in control also meant trying to manage, contain, and avoid her mental and emotional distress without support:

*The curtain dropped on what I feel inside, and even last week, I just really felt that I made a stride forward, and even [my husband] couldn't see it. I am so practicing at hiding. To break that wall down - that is all I have left holding me together. Why on earth would I jeopardize that? Why would I ask for a cathartic experience when there is absolutely no support?*

Of the six participants, Amy and Elyse appeared to have the lowest level of self-efficacy, at the time of the interview. They had stopped medication prematurely, for various reasons, and were attempting to manage their symptoms on their own. Their level of self-efficacy was reflected in their coping strategies: avoidance; denial; resistance; overworking; and withdrawal. Further, they acknowledged a sense of hopelessness and helplessness, which seemed to hinder their willingness to seek help and engage in various aspects of life, to avoid the impact of self and social stigma.

Skye had been diagnosed with bipolar disorder which had been pharmacologically treated since her teens. She stopped all but one of the psychotropic medications, early in her pregnancy. However, Skye discontinued the one medication, during her pregnancy and had been coping and managing well with her mental illness at the time of the interview. However, unlike Amy and Elyse, this did not result in a relapse, but rather Skye demonstrated a high level of self-efficacy, healthy self-esteem, and effective self-care. Further, Skye seemed to have a low level of self stigma and did not indicate feelings of shame, blame, and guilt; but rather demonstrated resilience to the negative effects of stigma and had a sense of ambivalence about her experience of maternal mental illness. Having support from her spouse and family and their vigilance and awareness of signs were also factors in her level of self-efficacy. This was interesting, especially being the youngest participant (18 years of age when pregnant and age 20 at time of interview)

with a history of bipolar and anxiety disorders. She was proactively engaged in finding useful resources, in reading to increase her knowledge and understanding of mental illness, and in learning new skills to manage her mental and emotional lability and the challenges of parenting. Skye described how she learned to monitor and manage her moods and how she taught herself effective coping strategies:

*Actually, I was off medications since I was pregnant. I have been doing really well. There was a book called the “Anxiety & Phobia Workbook.” I got that and that helped out big time actually. ... So I basically did it myself. ... I have learned to tell when things are coming, you know? My husband looks out for the signs, like for instance, when a manic sign is coming, he takes my bank card away. With the irritability, I learned to basically control for the most part, except for when PMS – that kind of adds to everything - that is pretty bad, but with the lows I have learned to completely control them now. It is amazing - like if I feel like I want to crawl into bed and turn off the lights and not do anything with life, I force myself to get up and do something productive that I haven’t done in a long time and I will go and run all these errands. It kind of pushes me to get out of that state, and it actually works really well because you feel like you have done something, and you feel proud, and it builds you up and gets you out of that low.*

Sue seemed to have a sense of self-efficacy despite not taking psychotropic medication for her maternal mental illness. Being in control was an important element in her ability to cope - who to share with and who not to, and having support. In addition, Sue made it clear when accessing mental health care that she did not want to use psychotropic medication: *One of the first things that I said was, “I did not want to take drugs.”* Sue was very proactive in managing

her maternal mental illness, had a sense of ambivalence, and chose to frame her experience in a positive manner:

*I just thought to myself that I don't have any control of it. It doesn't matter what I do. I eat really well; I go for walks; I exercise; I was in prenatal yoga; I just tried to enjoy it because I thought it might be the only time.*

However, being in control, for Tina, was choosing to continue taking the medication, taking a very positive approach to dealing with negative social stigma, having a support system which was facilitated by a family history of mental illness (also true for Skye), and having a sense of ambivalence about her experience with maternal mental illness, the expectations of motherhood, and the influence of stigma, demonstrating her level of self-efficacy:

*I guess my approach to [self stigma] had been to not be concerned with that sort of thing and to live my life and to live it in a way that I can be the happiest and this is the way that I am the happiest, and so I don't think of it past that.*

Being in control was a factor when Gabby decided not to take the recommended medication, during pregnancy, despite her symptoms and risk, and was greatly influenced by self stigma and feelings of fear, shame, blame, and guilt. Consequently, this decision seemed to reflect a sense of self-efficacy as she lacked the insight and awareness of her increasing postpartum symptoms, until her physician recognized it. At the time of the interview, Gabby (2 ½ years postpartum), was coping well on medication, although she had a sense of ambivalence about it. Further, she admitted that having twins helped justify the need to be on medication, indicating the insidious nature of self and social stigma. Having a system of support and being

able to share with other moms helped normalize her experience which was also a factor in her level of self-efficacy.

**Women's advice for maternal mental health care.** The women had several suggestions and recommendations about how to improve the care they received. Amy for example said:

*Every time someone is coming in with depression through pregnancy, I mean, keep them under observation for pity sake. If you bring up an alternate diagnosis, follow it through!! That was ridiculous. You know, if you had asked us two weeks later how things were going, we would have told you it was going "down the toilet" and that would be all that we would have said. If there is actually an openness to, "Well, you can call me and see me again." You have to schedule that. There has to be a set protocol for follow-up and assume that this is going to be a patient that you are likely going to be seeing and checking up on, for probably 2 years. And, educate the patient to stay on medication one year after you are well, to avoid recurrence. Educate them about family decisions." We ended you not having any more children because of this problem and this fear. We made decisions that we just probably shouldn't have and didn't have to. Why was there not support in that aspect?*

Gabby saw value in having a support group:

*I was very lucky that the women in my neighborhood contacted me and got me involved. But maybe, that could be something that they could improve - just making a moms' group time more obvious and have easy access to that. Because if I didn't have that, I think that it would be isolating.*

Tina thought that a mom's group could, on the one hand, be helpful to some, but on the other hand, it could be a hindrance:

*it[A support group] could be helpful, but on the other side of that is the more appointments you go to, if you have other children, it can sort of add a bit of stress as well, just trying to find childcare for them and trying to get to the appointment. So, it is a bit of a tricky situation. I believe that providing childcare would be a huge help for people.*

Tina also suggested better follow-up and having access to a counsellor:

*It would be very helpful. ...Only meeting once per month would not have been much help at all, had I not immediately started medication and started to feel better. I think that just the frequency of access would need to be improved.*

When asked what additional mental health care services could be offered, Skye stated:

*Well, counselling I find actually to be more effective than psychiatry, in my opinion because compared to psychiatry, they are looking for more than just a medication way to help you. Whereas, counselling, sometimes you just want to talk. When you are pregnant, you can barely go on any medications anyways, so psychiatrists aren't quite as helpful as they would be outside of maternity.*

Skye spoke of the possible misconception some people may have about seeking care for a maternal mental illness and validated the importance of being able to talk:

*Sometimes the word 'psychiatrist' or 'psychologist' can be scary and overwhelming to go to. However, hearing 'counsellor', you are just thinking that they are someone to talk to. I have always felt more comfortable with counsellors. Also, to have someone checking up on you - like how you have been doing - like calling every few months to check on you. ... just kind of quick follows over time, but it is good to check if they should be back in the program or if they need more help because then that feels like you aren't asking for help,*



*you are being having it offered. You are more likely to take the help, if it is offered, rather than if they asked.*

Skye also suggested providing information and education:

*For other people, that would be great to learn [about coping with anxiety]. It would be cool also if they could have someone influential in your life, like I said, my husband or mother, to help with the coping because for instance, like I said, my husband can tell when things are coming and he can help out with the process and it is good to have someone like that. And it is good if you had kind of a group and they were able to bring someone like [family or husband] with them so that person can also see what they should be looking for and better understand what that person is going through.*

Elyse suggested getting a call for follow-up: *because a lot of people won't phone, won't reach out because I know that I wouldn't have picked up the phone.*

In sum, the women's suggestions for providing mental health care services emerged around four areas: a) follow-up frequency and access; b) information and education; c) support; and d) therapeutic approach.

**Advice to other women.** Each participant was asked what advice they would suggest for other pregnant and post-partum women having mental health concerns and having to access mental health care services. Five participants encouraged women to normalize challenges they may face by knowing that they are not the only ones going through this experience, by recommending that they learn effective coping strategies and gain better insight of their mental health struggles by reading about it, and by encouraging other women to take the medication if they need it and to continue until they are beyond the risk of relapse.

Gabby stated that *if I thought that somebody was in trouble - I would just tell them to go see their family doctor and get care*. Sue's advice to other women was:

*Just to know that mental health care is there for a reason; and they aren't the first and they certainly won't be the last; and to not be embarrassed about getting care because it is here for a reason - there is obviously a need. That's all.*

According to Elyse:

*I would say to be honest with yourself because if you are not, you are never going to deal with it and I don't know, just realize that you are worth it even though you don't think you are. [You need to ask for help] if you need it, then to actually continue with it until you are kind of over it. It is really tough [taking medication], but logically you know that you should [take meds]. I don't know how to tell you about getting over not wanting to, but you need to. Because a lot of people won't phone because I know that I wouldn't have picked up the phone.*

Tina's advice to other women was: *just not to hesitate to initiate whatever help you need, as early as you can. If you feel that you need it, because it only gets worse, if you are trying to cope on your own*. Skye advised women to be proactive, learn new skills, and get information:

*To make sure that people know that you don't have to solely rely on medications all the time because I mean that it is good to have - don't get me wrong - but if you think that medications are going to save everything, you aren't that well off in the end. You have to have a backup - like knowing how to get up and out of bed and knowing when to give away your credit card and saying that I shouldn't have this right now. They should also know when to ask for help. That kind of stuff is important - medication you can't rely on all the time... And, reading about it does help, like that "Manic" book.*

Like Elyse, Skye also indicated that it was more difficult to ask for help, but will more likely take it if offered.

In sum, the participants' advice for other women dealing with maternal mental illness emerged into the following factors: a) being proactive in seeking help; b) normalization and shared experience; c) support and connection; d) taking prescribed medication; e) learning coping strategies; and f) decreasing shame.

## **CHAPTER 5: DISCUSSION**

This chapter provides a summary and discussion of the findings in terms of the bio-psycho-social dimensions of women's lived experience of having maternal mental illness and the impact of stigma when accessing mental health care. These findings are considered in terms of the literature reviewed as well as new literature brought to light with this study. In particular, Brown's Shame Resilience Theory (2006) provides a framework for findings. Implications for practice, strengths and limitations of the present study, and areas for future research are discussed.

### **Restatement of Study's Context**

The research on maternal mental illness has been conducted predominately on postpartum depression (PPD) using quantitative inquiry, which has primarily focused on diagnostic issues, prevalence, associated biological factors and the use and safety of pharmacological treatments and mainly representing a biomedical orientation. There is limited research literature regarding other variants of maternal mental illness, such as: a) antepartum anxiety and/or antepartum depression; b) antepartum and /or postpartum psychosis; c) postpartum anxiety; and d) bipolar/affective co-morbidity. These are often represented using the umbrella term of postpartum depression (Brockington, 2004). For the purpose of this study, the term maternal mental illness was used to refer to any admixture of these conditions.

The choice to use interpretive description (Thorne, 2008) as the research method allowed the uniqueness of each participant's experience of having maternal mental health problems and her meaning-making process to shine through illuminating the complex interplay of various bio-psycho-social factors. This approach revealed a shared meaning of participants' lived experience

of mental illness, in the midst of the entrenched social stigma associated with maternal mental illness and the pernicious cultural myths and social expectations of motherhood and reproduction. What emerged from the study was the importance of going beyond a biomedical approach (in research, assessment, treatment, and health care practice) when caring for mothers with mental health problems and their families. In addition, the importance of health care providers to being sensitive to and acknowledging, considering, and addressing the socio-cultural context and the psycho-social implications of stigmatization which plays a role in women's experiences of mental illness, accessing mental health care, and their health outcome.

### **Integration of Findings with Existing Literature**

Despite the differences between the women's experiences, there were commonalities intersecting their stories and evidence of a shared meaning of living with maternal mental health problems and its bio-psycho-social impacts on various aspects of daily life, including their ability to manage life and mothering, their relationships with spouses, family, and friends at the workplace and/or school, as well as their sense of self and wellbeing. The study findings identified a variety of biological and psycho-social risk factors, which seemed to contribute to the women's experience of maternal mental illness and their treatment experience and health outcome based on a biomedical approach.

**Biological and biomedical factors.** Several biological risk factors emerged from the women's experience of maternal mental illness that were also identified in the research literature (Gold, 2002; Kalra & Einarson, 2006; Marcus, 2009). These contributing factors included anxiety and depression co-morbidity, a personal and a family history of mental illness, a previous history of PPD, treatment engagement, and the risk of relapse.

A higher co-morbidity between anxiety and depression than previously thought has been recognized, which is associated with an increased risk of developing PPD (Austin et al., 2007; Bowen et al., 2008; Matthey et al., 2003). Further, research has indicated that women who experience prenatal anxiety are three times more likely to report PPD symptoms compared to women without anxiety (Austin et al., 2007; Bowen et al., 2008); and women with bipolar disorder are extremely vulnerable to maternal mental illness, during and after pregnancy (Gold, 2002). The current findings supported previous research identifying the importance of assessing and addressing both anxiety and/or depression for women during pregnancy, rather than only focusing on depression during postpartum (Austin et al., 2007; Bandelow et al., 2006).

At the time of seeking care, all of the participants reported experiencing symptoms of anxiety during pregnancy, although some also described symptoms of depression, and for one woman, psychosis. All of the women had a previous personal history of mental illness, for which five had been treated pharmacologically. Most had a history of anxiety, and two had a previous episode of PPD. In addition, during adolescence, Skye was diagnosed with bipolar disorder and Gabby had an eating disorder. Both, Skye and Tina had a family history of mental illness (bipolar and anxiety, respectively). Their physicians recognized and had immediately referred them for mental health care, aware of their multiple risks for developing PPD.

Amy and Elyse's previous history of PPD was another contributing factor in developing maternal mental illness. They both took medication for a while during the first postpartum period, but then discontinued without consulting their physician. Although they had PPD after their first pregnancy, they were never informed of their increased risk of developing a mental illness with subsequent pregnancies, nor did they seem to realize symptoms could develop during pregnancy. Both of these women did not seek help in a timely manner. In fact, they delayed

seeking help until they reached a felt crisis point and felt incapacitated and unable to manage daily functioning. Amy delayed seeking help until she was experiencing disturbing visions and thoughts of harming herself and her child, consistent with Gold's (2002) research, which found that women had a 50% higher risk of recurrence of PPD following subsequent pregnancies. When PPD goes untreated or undertreated, women are at risk of developing psychosis (Gold, 2002). According to Einarson (2009b), although information regarding the safety and efficacy of psychotropic medication is readily available, women with maternal mental illness are often undertreated because of a lack of knowledge or information by health care providers, as well as women and their families. This study revealed the need for optimal control of maternal mental illness during pregnancy and postpartum and the importance of careful monitoring for high risk women (Einarson, 2009b). Further the findings of the present study highlighted the importance for health care professionals to inform and educate women and their families about mental health status and diagnosis, implications of pharmacological treatment engagement, and risk of relapse, also identified in other research (Cohen et al., 2006; Gold, 2002; Marcus, 2009).

Treatment engagement was a factor in the participants' experience of mental illness. In the context of this study, treatment engagement referred to participants' compliance with taking psychotropic medication as prescribed by a health care professional. Five of the six participants were prescribed psychotropic medication as a result of accessing mental health care services, and four of them discontinued and/or postponed taking the prescribed medication for a variety of reasons (e.g., side effects, cost, stigma), without consulting their physician. The four women seemed to lack insight and awareness of being at risk of relapse. Furthermore, of the four women who discontinued the pharmacological treatment, two participants had a relapse and at the time of the interview described an ongoing struggle with debilitating symptoms of anxiety and

depression beyond their second postpartum year. This was also noted by Cohen et al. (2006) who found the risk of relapse with premature discontinuation of pharmacological treatment was 68%. underscoring the importance of women understanding and being clearly informed and educated about the implications of treatment engagement when medication is prescribed and when dispensed.

Researchers have noted that an under treatment of, or a failure to address maternal mental illness leaves women more vulnerable to ongoing mental health problems, greatly impacting a mother's opportunity for optimal health and wellness (Einarson, 2009b; Matthey et al., 2003; Seto et al., 2005). It is vital that women and their families receive information and support when physicians prescribe psychotropic medications, especially when no other treatment options are explored (Gold, 2002; Marcus, 2009). According to Tufano (2000), with a biomedical approach "treatment is given in a medically prescriptive manner" (p. 133), which privileges pharmacological interventions over psycho-social approaches. Similar to Wardrop and Popadiuk (2013), the findings revealed the need to expand a biological focus by considering a woman's socio-cultural context and the psycho-social aspects of her experience of maternal mental illness, when providing mental health care.

**Psycho-social factors.** In addition to the biological risk factors identified in the present study, several psycho-social risk factors were also implicated in the participants' experience of maternal mental health and health outcome. Similar to the research literature that identifies support as playing a key role in developing and/or exacerbating maternal mental illness (Gold, 2002; Kalra & Einarson, 2006; Marcus, 2009), all participants commented that level of support was a factor in their experience of living with a mental illness



However, Amy's lack of family and social support contributed significantly to her ever-increasing mental and emotional distress. As a result of job relocation, Amy lacked a family support system due to their distant proximity. Furthermore, Amy lacked the family's emotional support because their religious beliefs did not recognize mental conditions as an illness. This prevented Amy's family from accepting her legitimate concerns, which deepened her feelings of isolation. These psycho-social risk factors had a significant impact on Amy's experience of mental illness and health outcome, yet were not identified or considered by the physicians when assessing symptoms and recommending pharmacological treatment.

Another psycho-social factor in participants' experience of mental illness was the lack of specific information, knowledge, and insight about their mental health status, which perhaps increased some women's risk of developing and/or exacerbating their mental health problems, also noted in the research literature (Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005; Pinto-Foltz & Logsdon, 2008). For example, maybe if Amy and Elyse had received the necessary information and education about PPD with their first episode, they would have been more aware of their risk during their second pregnancy. They may have been more aware and had the insight to recognize the symptoms and not delay seeking care until reaching a crisis (McCarthy & McMahon, 2008). Further, if they had the relevant information from their primary care provider and mental health care professionals, they would have been aware of the implications and risk of prematurely discontinuing the prescribed medication and their risk factors for relapse (Cohen et al., 2006; Marcus, 2009). This lack of knowledge and insight seemed to interfere with their ability to manage their mental health problems and challenges of mothering (DaCosta et al., 2006; McCarthy & McMahon, 2008).

These findings suggested the importance of providing information (e.g., increasing awareness of the signs and symptoms, the bio-psycho-social risk factors, medication options and compliance, and psycho-social implications) and helping women and their families to recognize symptoms, seek help, and manage maternal mental illness in a pro-active manner. The importance of primary care and mental health providers taking the time to inform and educate each woman and her family is also noted in the research literature (Cohen & Nonacs, 2005; Dennis & Chung-Lee, 2006). Both the research literature and the findings of the present study identified that ongoing mental health problems have significant bio-psycho-social impacts on a woman's quality of life, physical and emotional well-being, social interactions, self-care and sleep quality (Bowen et al., 2012; Da Costa et al., 2006; Seto et al., 2005).

In this study, these impacts were also reflected in the participants' marital relationships, their children's behaviour, their level of self-care and their sense of self and self-efficacy, psycho-social factors also noted by other researchers (Cohen & Nonacs, 2005; Dennis & Chung-Lee, 2006). Untreated or severe maternal mental illness had profound effects not only on the new mother and baby, but also on her partner and other relationships (Matthey et al., 2003). All the women in this study indicated that having a mental illness impacted their relationships and various social interactions with their spouse, family members, friends, and co-workers, although occurring in varying ways.

Of note, both Amy and Gabby's spouses became depressed one-year postpartum, which proved to have a psycho-social impact on the whole family. According to one study (Goodman, 2004), the incidence of paternal depression, during the first postpartum year, ranged from 24% to 50% among men whose spouse had PPD; and the strongest predictor of depression in fathers during postpartum was the presence of PPD in their spouse.

In summary, findings revealed the importance of providing timely and appropriate access to mental health care services not only for women with mental health problems, but also the need to include spouses and families in the assessment, management, and education of maternal mental illness (Gold, 2002) and the need to provide access to services, resources, and support for a longer period of time, beyond the first postpartum year. In addition, findings highlighted the importance of using a bio-psycho-social approach rather than only a biomedical approach when assessing, treating, and supporting mothers with mental health problems and their families (McCarthy & McMahon, 2008; Wardrop & Popadiuk, 2013).

**Infertility.** Infertility and the process of IVF were contributing factors in three participants' experience of maternal mental illness. This was an interesting and unexpected finding. My review of the literature did not reveal the increased risk of maternal mental illness for infertile women and use of IVF. It was only through the course of the interview I learnt that three of the six participants conceived using IVF and how this process was part of their experience with maternal mental illness.

Infertility, a prevalent problem that affects about 15% of childbearing age women, refers to the inability to conceive after at least one year of regular unprotected sexual intercourse, or after 6 months, if a woman is over 35 years old (Leon, 2010; Olshansky, 2004). The ages of the women in this study who struggled with infertility ranged from 31 to 39 years of age. One study (Punamaki et al., 2006) showed that mothers who used IVF continue to be at increased risk of depression and anxiety during pregnancy and were vulnerable to complications at pregnancy and labour/delivery, such as premature and low birth weight babies. Both Sue and Tina had premature labour and deliveries, and similar to other research (Ellison & Hall, 2003; Fisher,

Hammarberg, & Baker, 2005), Tina and Gabby felt their mental illness was intensified by their multiple births, which further increased their risk of developing PPD.

The experiences of the participants who used IVF was reflected in the research literature that associated a history of infertility and compounded pregnancy losses with increased levels of emotional distress and anxiety. Similar to findings reported in a study that associated a history of infertility and compounded pregnancy losses with increased levels of emotional distress and anxiety (Ellison & Hall, 2003), the three participants, Sue, Abby and Tina, identified the cause of their antenatal anxiety as being specific to the fear of miscarriage and/or being overwhelmed with the prospects of having twins. They acknowledged various aspects of the IVF process as significant contributing factors to their maternal mental distress, such as using fertility drugs for years, enduring multiple miscarriages, experiencing a difficult and/or premature labour and delivery (Tina, Sue), and having a multiple birth (Abby, Tina).

Each referred to the process of IVF, which lasted three years on average, as being the most difficult and stressful challenge they had ever experienced in life. This was similarly noted in a 10-year follow-up study of women using IVF to conceive, conducted by Sundby and colleagues (2007 as cited by Olshansky & Sereika, 2005) who reported that women remembered the period of infertility as a difficult time in their lives. What emerged from the findings of this study was a shared experience of feelings of loss, fear and pressure that impacted their mental health. These factors suggest that the psycho-social elements of women's experience are important considerations when providing care, and confirm research suggesting that women with a history of infertility, using IVF, and/or having multiple birth, who experienced severe anxiety and stress, are at risk of developing a maternal mental illness; and therefore, should be monitored closely before, during, and after pregnancy (Fisher et al., 2005; Olshansky & Sereika, 2005;

Punamaki et al., 2006; Slade, O'Neill, Simpson, & Lashen, 2007). Although the homogeneity of the study sample reflected a narrow range of women's experiences, the occurrence of half the sample experience infertility and IVF provided a unique element of analysis, revealing psychosocial factors otherwise masked with the biomedical approach.

**Accessing mental health care services.** All participants initially sought help for their distressing symptoms from primary care providers, either their family physician or obstetrician. This confirmed research that indicates women with maternal mental illness are more likely to seek help from primary health care providers than mental health professionals (Gold, 2002). Many of the women in this study described their relationship with their primary physician as a vital factor in their experience with mental illness and accessing care, also noted in the research literature (Dennis & Chung-Lee, 2006; McCarthy & McMahon, 2008; Wardrop & Popadiuk, 2013); however, most of these studies found that women did not often feel supported by their health care providers, which impacted their experience of maternal mental illness and accessing care. Women reported feeling stigmatized by attitudes of some health care providers who minimized or were reluctant to respond to their emotional and practical needs and concerns, which impacted access to mental health services and the level of care received (Ahmed et al., 2008; Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005). Interestingly, all of the participants in this study felt supported and validated by their primary family physician, which points to the importance of having validating and mutually empathic relationships (Dennis & Chung-Lee, 2006; McCarthy & McMahon, 2008; Wardrop & Popadiuk, 2013).

The research literature indicated that pregnant and postpartum women often receive inadequate mental health care, and/or do not seek help, due to a lack of and/or limited access to mental health care services; and they are often under-diagnosed by health care providers who

may minimize or discount women's symptoms of emotional distress (Dennis & Chung-Lee, 2006; Marcus, 2009; Pinto-Foltz & Logsdon, 2008). However, this was in sharp contrast to this study as all of the women's primary care providers recognized their symptoms of anxiety and their risk of developing PPD, were aware of the need to access mental health care in a timely manner. This indicated the importance of the early identification of risk factors, and timely access to mental health care. Most of the participants described a felt sense of being in crisis, having reached a critical point, and for some, a sense of desperation and dire need of help, at the time of accessing care, which would indicate a need for crisis support while these women waited to access mental health care services, which was also noted by McCarthy and McMahon (2008).

The issue of follow-up care emerged as a factor in participants' experience of maternal mental illness, treatment engagement and satisfaction, and their health outcome. Other research has identified the need for regular follow-up for maternal mental illness, especially women who are at a higher risk (Einarson, 2009b; Gold, 2002; Le, Munoz, Ippen, & Stoddard, 2003; Wardrop & Popadiuk, 2013). But what constitutes high risk? The findings of this study suggest the value of clearly determining criteria for follow-up visits and that focusing on pharmacological treatment and symptomology overlooks psycho-social factors at play (McCarthy & McMahon, 2008). It is important to expand the assessment of women's mental health risk beyond biological symptoms, standardized scales and questionnaires, by including and being sensitive to women's socio-cultural context and the psycho-social factors in their lives influencing their risk (Wardrop & Popadiuk, 2013).

Although primary physicians in this study were well informed about symptoms and risks of maternal mental health, treatment follow-up was a concern for some. Researchers found that when physicians pharmacologically treat pregnant or postpartum women for mental illness, they

were more cautious and tended to undertreat (Cohen & Nonacs, 2005; Einarson, 2009a; Nonacs & Cohen, 2002; Pinto-Foltz & Logsdon, 2008). Some of the participants stated their family physicians were uncomfortable and reluctant to adjust the usage and dosage of psychotropic medication initially prescribed by mental health care professionals. For example, when Amy was seen on an emergency visit, her obstetrician had sought consultation with the care provider by phone, in order to discuss adjusting the prescribed psychotropic medication because Amy was having increasing symptoms of psychosis; however, this attempt was unsuccessful. This indicated that mental health care providers should be available for consultation with, and to support, family physicians and other health care practitioners in the community, as well as being available to answer questions about the program, screening for PPD, and treatment options, in addition to providing direct client services (Bowen et al., 2008).

The effort and difficulty of gaining access/re-access to mental health care services seemed to be a factor in some women's (Amy and Elyse) treatment engagement/satisfaction and health outcome and also seemed related to stigma/shame and their sense of self-efficacy, their sense of self and their ongoing symptoms, also noted in the research literature (Corrigan et al., 2009; Corrigan & Wassell, 2008)

***Treatment engagement, satisfaction, and health outcome.*** Consistent with the literature (Marcus, 2009), participants' treatment engagement increased when women were screened by their health care provider and informed about their depressive state. Most of the participants seemed to lack the insight or awareness of their symptoms, but their physician had identified their risk and promptly referred them to the program. As Dennis and Chung-Lee (2006) report, some mothers were reluctant to disclose feelings of emotional and mental distress without having

the question asked first by their physician. This was also indicative of the importance of their relationship with and the support of their family physician.

Researchers have identified inappropriate or lack of assessment as a health care barrier for women with maternal mental illness (Dennis & Chung-Lee, 2006; McCarthy & McMahon, 2008). Amy was the only participant who spoke directly about the screening process when accessing mental health care services and the tools and questionnaires used to determine the level and severity of maternal mental and emotional distress. She believed the screening was inadequate in identifying and addressing her symptoms of psychosis and was a barrier in terms of accessing appropriate and ongoing care. She reported that she had never been asked directly by the attending physician about these possible symptoms (visions and thoughts of harming herself and her daughter) during the interview. Further, the screening process did not identify her lack of family and social supports, feelings of isolation and other possible psycho-social factors which would have been captured had a bio-psycho-social approach been added.

The level of participants' treatment engagement, satisfaction, and health outcome varied when accessing mental health care, however, did not depend solely on the efficacy of the medication. Similar to other research, other factors emerged which seemed to contribute such as a) lack of information, feedback, and education from health care providers regarding their mental health status and risks at the time of diagnosing and prescribing treatment (Dennis & Chung-Lee, 2006; Marcus, 2009); b) the biomedical focus on using psycho-pharmaceutical interventions and lack of other treatment options (McCarthy & McMahon, 2008); and c) personal experiences of stigmatization (Dennis & Chung-Lee, 2006; Pinto-Foltz & Logsdon, 2008).



What emerged as an essential aspect of women's experience of maternal mental illness, treatment engagement, satisfaction and health outcome was the amount and the quality of the information/education they received from health care providers in regards to risks and implications of maternal mental illness (for women, spouse, and family), signs/symptoms, treatment engagement and options, and psycho-educational resources.

Researchers have identified physicians having insufficient time during consultation and the tendency to prescribe medication, rather than talk, to alleviate symptoms reinforcing feelings of inadequacy and stigmatization which were health care barriers for women with maternal mental illness (Dennis & Chung-Lee, 2006; McCarthy & McMahon, 2008). Although participants felt supported by their family physician, some participants spoke of the amount and quality of time and “talk” they received from mental health care professionals, and how it influenced their treatment satisfaction. Several participants spoke of and indicated a lack of talking, feedback, and information when accessing mental health care services, while Skye for example commented on the importance and benefit of “talk therapy” for women dealing with mental health problems. This reflected previous research which noted that women preferred to have talk therapy with someone who was nonjudgmental rather than receive pharmacological treatment (Dennis & Chung-Lee, 2006; McCarthy & McMahon, 2008).

Research has found a significantly greater improvement for maternal mental illness in women who received counselling and psychotropic medication during pregnancy (Bowen et al., 2012); yet only one of the five of participants who were on medication also had the opportunity for counselling. As in other studies (McCarthy & McMahon, 2008; Wardrop & Popadiuk, 2013), the participants expressed a desire for the therapeutic relationship to be about more than medication. They wanted health care providers to be more engaged, aware of and sensitive to the

unique concerns and needs of women with maternal mental illness, in addition to creating a safe and non-judgmental environment to facilitate their ability to talk freely and get necessary feedback and information.

***Stigma and accessing care.*** The shared experience and shared meaning of accessing mental health care services revealed aspects of self stigmatization in women's experience of maternal mental illness. Participants had personal experiences of perceived and enacted stigmatization, through their relationships, in their social interactions, often in the form of inappropriate questions and unsolicited advice and/or comments from others, including health care professionals. Several researchers have similarly found that women's experience of stigma of maternal mental illness was impacted by interactions with health care providers and by perceived dismissive attitudes which deter women from seeking help and accessing mental health care, and impact treatment engagement/satisfaction and health outcomes (Ahmed et al., 2008; Dennis & Chung-Lee, 2006; Pinto-Foltz & Logsdon, 2008).

Some researchers have argued that women treated in primary health care settings for their mental health problems report less stigma in getting help than women who were treated elsewhere (Weissman et al., 2004). Some participants, Amy and Skye, reported experiencing dismissive attitudes and comments from health care providers that impacted their treatment engagement, satisfaction, and health outcome, which seemed associated with a fear of disclosure, denying and/or minimizing the severity of their symptoms, and increased self stigmatization, similar to other studies (Dennis & Chung-Lee, 2006; Marcus, 2009; Pinto-Foltz & Logsdon, 2008).

On the other hand, despite the experience of stigmatization, low treatment engagement and treatment dissatisfaction when accessing mental health care services, Skye's sense of self and health outcome were not negatively impacted. At the time of the study, when both of these women were two-and-a-half years postpartum, Amy was experiencing ongoing mental health problems that continued to negatively impact her spouse, her children and herself, whereas Skye was coping well with her mental health and was engaged in a proactive manner. This seemed to be related to having some resiliency to self stigma and a level of self-efficacy. Corrigan and Wassell (2008) also noted a link between low self stigma and self-efficacy. The study findings pointed to the need for more transparency, sensitivity, and self-reflexivity on the part of the mental health care providers to minimize their role in and the impact of stigma on women's experience with maternal mental illness, treatment engagement, and health outcomes (McCarthy & McMahon, 2008).

Similar to findings in Dennis and Chung-Lee (2006), participants' experiences of stigmatization while accessing mental health care services revealed the psycho-social implications for women being immersed in a biomedical model, which focused on diagnosis and pharmacological interventions, and has traditionally placed the site of the problem with the individual woman and her body (Koniak-Griffin et al., 2006). The findings indicated the importance and need for health care providers to be much more aware and sensitive to how they and/or the elements of mental health care services may be contributing to the woman's experience of stigmatization (McCarthy & McMahon, 2008).

***Stigma and motherhood.*** Similar to the research literature (Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005; McCarthy & McMahon, 2008; Pinto-Foltz & Logsdon, 2008; Vogel, Wade, & Haake, 2006, 2007), stigma played a central role in participants' experience of

maternal mental illness, in seeking help, accessing appropriate mental health care, and in their treatment engagement and health outcome. However, the manner in which participants experienced stigma and its impact varied.

Consistent with the research literature, the shared experience and shared meaning of the participants' experience of maternal mental illness were indicative of the insidiously and deeply entrenched nature of the social expectations of joyful motherhood, perfect and intensive mothering, and normal and natural reproduction (Arendell, 2000; Choi et al., 2005; Cosgrove, 2000; Koniak-Griffin et al., 2006; Woollett & Boyle, 2000). The women's shared experience and shared meaning of mental illness stigma emerged either internally (impact on relationships and sense of self) or externally (the harmful effects of prejudice and discrimination and negative evaluation from others), as has been noted in the research literature (Corrigan & Wassell, 2008; Corrigan & Watson, 2007). All the women were aware and had a common understanding of the social misconceptions and the negative stereotypes associated with mental illness, often used as pejorative social labels. Being labeled "crazy," "unfit," "weak," and "defective," was a shared concern for most of the women, which impacted some women's willingness to seek help and/or engage in treatment, something that is confirmed in the research literature (Corrigan & Wassell, 2008; Kenny, 2001).

Similar to other studies, some of the participants in this study had internalized a sense of being a "bad and/or unfit mother," or feared being perceived as "less-than-perfect," which lead to feelings of anger, shame, blame, and guilt fostering the fear of being labeled (Dennis & Chung-Lee, 2006; McCarthy & McMahon, 2008; Pinto-Foltz & Logsdon, 2008). For the participants, having a maternal mental illness was not only about experiencing symptoms and the stigma associated with mental illness, but also about how they perceived themselves and how they felt

they measured up as a woman, mother, and wife. This spoke of a deeper level of stigmatization and the underlying social scripts affecting and dictating the everyday lives of women living with maternal mental illness inextricably linked to their sense of self, a feeling of shame.

***Stigma and infertility.*** Notably, another layer of the social scripts dictating the norms of motherhood and womanhood were revealed in the lived experience of three of the women who experienced infertility and had used IVF (Ellison & Hall, 2003; Leon, 2010). These findings presented an example of the intersection between the biomedical/biological ideology, the medicalization and mechanization of reproduction and the socio-cultural context of women's lives and the impact this can have on how they perceive themselves as a woman with a reproductive body and as a mother with a mental illness. The negative stigma surrounding infertility, the use of fertility drugs and IVF to conceive, and multiple births illustrated the interconnections between social notions of motherhood and the medicalization of female reproduction, as being natural, normal, and compulsory for all women (Ellison & Hall, 2003; Leon, 2010; Slade et al., 2007).

The shared experience and shared meaning of infertility was evidenced by the three participants who identified the negative social stigma associated with the use of fertility drugs, and especially multiple births, as a major factor in their experience of stigma. Further, they had a shared experience of being judged, often as a result of intrusive and inappropriate questions and comments from others. They described their experience of self stigma in varying degrees which included: being perceived as having "artificial babies" and "not normal and natural," being a reflection of the marital relationship, being angry about her age or body, having feelings of shame, blame, and guilt and a sense of not belonging or not fitting in with other mothers, also identified in other studies (Ellison & Hall, 2003; Leon, 2010; Slade et al., 2007). This study

highlighted the importance of identifying and addressing the psycho-social implications of infertility and the process of IVF in women's experience of mental illness and feelings of shame.

***Impact of stigmatization.*** In this study, the participants' shared experience and shared meaning of self stigma were interconnected with their sense of self. The research literature suggests that the impact of self stigmatization depends on the degree of identification and internalization of the negative social stigma associated with maternal mental illness, the unrealistic expectations of motherhood and the medicalization of reproduction, which undermine women's sense of self-esteem, and thus influence their sense of self-efficacy (Corrigan et al., 2009; Corrigan et al., 2006). The sense of self-efficacy is related to their belief, confidence, and sense of personal adequacy, in their own ability to manage the various challenges of having a maternal mental illness (Corrigan et al., 2009; Corrigan et al., 2006).

Similar to this study, other studies indicated that women often under-report distressing symptoms to avoid being perceived as a bad mothers, and fear of having children apprehended if they revealed the level of their emotional distress and admitted to being unable to cope or manage their symptoms of mental illness and the demands of mothering (Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005; Einarson, 2009b; Marcus, 2009; McCarthy & McMahon, 2008). As in this study, others identified self stigma and self-devaluation as the main obstacle preventing women from seeking help and/or accessing care (Corrigan et al., 2006; Edwards & Timmons, 2005; Kenny, 2001; Tognazzini et al., 2008).

Another factor influencing the depth of self stigma revolved around being on medication and what meaning the participants made of it. Five of the six participants shared their experience of having a maternal mental illness, being treated with psychotropic medications based on a

biomedical approach, and the impact this had on their self-esteem. Findings of this study concur with the literature, which found that not only did self stigma reduce the motivation to seek care, but it also impacted compliance with recommended pharmaceutical treatment plans (Corrigan, 2004; Kenny, 2001), decreased treatment adherence, and resulted in early termination of treatment (Sirey et al., 2001; Vogel et al., 2006). Three women identified and internalized the negative self stigma of being a mother with mental illness who was taking psychotropic medication to cope, which they perceived as a failure, defect, or weakness on their part. As in this study, other researchers have identified the stigma attached to the use of certain psychotropic medication, especially, antipsychotics, and associated with feelings of fear and embarrassment over the illness or the treatment, or because they were afraid to experience any kind of stigmatization because of the pharmacological treatment (Sajatovic & Jenkins, 2007; Sirey et al., 2001).

One participant with a medical background clearly associated certain anti-psychotic medications with being “*crazy drugs*” and deciding to not fill the prescription for fear of being labeled and judged as being “*crazy*,” which was interesting given her training in dispensing medication. Further, when Gabby started anti-depressants during postpartum, she shared her need to justify her use of medication as having twins, rather than being perceived as having a weakness or character flaw. This illustrated her strong, if unspoken, desire to avoid the mere association with taking certain psychotropic drugs which implied a simultaneous membership within the ranks of a stigmatized group, crazy mothers who may “*smother their babies*.” This was a clear example of label avoidance (Corrigan, 2004). This also highlighted the need for more training and education of all health care providers to increase the awareness, familiarity and sensitivity to the bio-psycho-social implications of stigma and women’s experience of maternal

mental illness. Studies indicated that health care professionals and students, such as doctors, pharmacists, and nurses, may hold stigmatizing views towards women with maternal mental illness, despite having training expected to enhance acceptance, sensitivity to and knowledge of patients with mental health (Gawley, Einarson, & Bowen, 2011; Thornicroft et al., 2007; Tognazzini et al., 2008).

In sum, the impact of self stigmatization and the fear of being labelled affected the participants' social interactions, willingness to seek help, the degree to which they disclosed their mental illness, their treatment engagement and health outcome, and their sense of self-esteem and self-efficacy. "When a person is stigmatized, she is branded in disgrace or shame" (Tufano, 2000, p. 113).

### **Conceptualization of Findings Using Shame Resilience Theory**

The participants' shared experience and shared meaning of the self stigma surrounding maternal mental illness in a biomedical context, and the underlying socio-cultural norms and expectations of motherhood can be conceptualized using the shame resilience theory (SRT) presented by Brown (2006). Shame resilience theory offers a working definition of shame as "an intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance and belonging" (Brown, 2006, p. 45). Shame, like self stigma, consists of "unwanted identities when women self-attribute, or when they perceive others as ascribing to them, a characteristic that undermines their self-ideals" (Brown, 2006, p. 46).

According to Brown (2006), shame is a psycho-social-cultural construct which plays a significant role in the lives of women:



The psychological component relates to the participant's emphasis on the feelings, thoughts, and behaviors of self. The social component relates to the way women experience shame in an interpersonal context that is inextricably tied to relationships and connection. The cultural component points to the prevalent role of cultural expectations and the relationship between shame and the real or perceived failure of meeting those expectations (p. 45).

SRT understanding of shame (i.e., self stigma) is a contextualized and multidisciplinary approach which brings together several complimentary theories, such as relational-cultural theory (RCT) and empowerment theory. Relational-cultural theory assumes "that all growth-fostering relationships and all disconnections are constructed within specific cultural contexts" (Brown, 2006, p. 49). Both relational-cultural theory and SRT identify connection, empathy and isolation as central to women's experiences and have a feminist perspective which focuses on the socio-cultural construction of shame; however, these also differ. SRT encompasses empowerment theory with central themes that consist of "the concepts of critical awareness, deconstructing, normalizing, and contextualizing as processes to facilitate connection, power and empathy" (Brown, 2006, p. 50). Therefore, using SRT as a means to conceptualize and analyze the bio-psycho-social dimensions of the participants' experiences and shared meanings of self stigma/shame and maternal mental illness was well suited to the methodological approach of interpretive description and the goals of the study.

Similar to SRT, some participants in this study reported feelings of being isolated, trapped, and powerless that were enmeshed in the rigid and unrealistic social/cultural expectations surrounding motherhood and mothering, which are often imposed, enforced, or expressed within relationships and experiences, analogous to Brown's shame web (2006);

The concept of a shame web illustrates how options are limited and expectations are far-reaching, reinforced at every turn and woven through numerous experiences and relationships. . . . It is the intricate weaving of these concepts that makes shame so powerful, complex, and often difficult to overcome (p. 46).

Aspects of the shame web identified in the findings of women's experience of stigmatization included psycho-social factors and context, socio-cultural norms and expectations of motherhood, the biomedical model of care based on the diagnosis of psychopathology with the privileging of pharmaceutical treatments, the medicalization of reproduction through the process of IVF, the depth of stigma/shame, and the sense of self-efficacy and sense of empowerment.

**Self-efficacy and shame resilience.** Consistent with other research (Corrigan et al., 2009; Corrigan et al., 2006; Gourounti, Anagnostopoulos, & Lykeridou, 2013), the participants' sense of *self-efficacy* was reflected in their ability to cope and manage their maternal mental health problems and in the strategies they used to resist, moderate, and/or mitigate the negative effects of self stigma on their self-esteem (feelings of shame, blame, and guilt) and/or in their social interactions (fear of being judged, rejected, and isolated). The findings revealed a relationship between the depth of self stigmatization (shame) and the women's sense of self-efficacy (shame resilience). Please note that the terms self-efficacy and shame resilience are used interchangeably. The deeper the shame, the more the women's sense of self-efficacy seemed diminished. In this study, women's sense of self-efficacy reflected a range of shame resilience which was influenced by several bio-psycho-social factors associated with the women's feelings, actions, reactions, and outcomes related to the experience of having a maternal mental illness and the self stigma/shame surrounding it.

Shame resilience theory provided a conceptual understanding of shame “through the development of a continuum schema and identified the strategies and processes women find effective in developing shame resilience” (Brown, 2006, p. 45). Shame resilience is determined by the cumulative impact of four continuums: a) the vulnerability continuum (level of acknowledgement of personal vulnerabilities); b) the critical awareness continuum (level of awareness a woman has about the social/cultural forces that shape her experiences and her ability to critically assess her personal experiences in this context); c) the reaching out continuum (measure of one’s ability to reach out to others to find connection and empathy and de-mystify the isolating properties of shame); d) the speaking shame continuum (the fluency with which a woman engages in thought and dialogue about shame and resilience) (Brown, 2006, p. 49).

Shame resilience appeared to be congruent with the range of self-efficacy found in this study, which was best conceptualized as a continuum: on one end, the main concerns of the participants were the fear of being labeled, judged, and rejected with feelings of being trapped, powerless, and isolated. And located on the other end, feeling empowered, connected/supported, and free from shame (i.e., self stigma), which reflected Brown’s findings (2006). Researchers (Vauth, Kleim, Wirtz, & Corrigan, 2007) have found that diminished self-efficacy undermined personal empowerment, as in this study. Corrigan (2006) defined empowerment as a complex phenomenon which defined a person’s sense of control over the decisions about all areas of life. Study findings paralleled Brown’s (2006) SRT, which emphasized the need to increase women’s sense of personal power by understanding the connection between their personal experiences of shame and their socio-cultural context.

**Being in control and empowerment.** Findings revealed that a sense of self-efficacy/shame resilience was connected to the women’s sense of being in control of certain

aspects of their mental health that allowed them to mitigate the harmful effects of social and self stigma and shame by deciding who to tell, and who not to tell, taking medication or not taking medication, and being proactive or not, which reflected a sense of empowerment. According to SRT, identifying and addressing women's shame web and enhancing their sense of control, choice, connection, and ability to affect change are essential in facilitating women's empowerment and shame resilience (Brown, 2006).

This study reflected other studies (Corrigan & Wassell, 2008; Keeton, Perry-Jenkins, & Sayer, 2008) that found women were less likely to experience self stigma when they believed they had control of their lives and their treatment, which for some participants served as a protective factor for their mental health outcomes. This sense of empowerment was associated with higher self-esteem, quality of life, social support, treatment satisfaction, and facilitated self-efficacy, also reported by other researchers (Brown, 2006; Corrigan, 2006; Corrigan et al., 2009). The present study's findings identified several psycho-social factors that seemed to influence women's sense of being in control, empowerment and shame resilience, such as treatment experience, the level of self-disclosure, coping strategies, ambivalence, and level of perceived support, connection and empathic relationship with health care provider.

***Treatment experience.*** Study findings concurred with several researchers who have identified a sense of being in control as a significant factor in women's experience of maternal mental illness and accessing care (Keeton et al., 2008; Pinto-Foltz & Logsdon, 2008). For some of the participants, being in control might have meant deciding whether to refuse, start, continue, and/or discontinue the prescribed psychotropic medication (discussed previously), although for some participants this proved to be a significant factor in the outcome of their maternal mental illness, especially in light of not having other treatment options such as counselling, support

group and peer support, and information available when accessing care. This was also found in other research which indicated that individuals with mental illness were less likely to experience stigma and shame when they perceived having control of their own lives and treatment (Corrigan & Wassell, 2008). The perceived focus on pharmaceutical treatments, lack of treatment options, and lack of resources/services and necessary information/education about their diagnosis and mental health status impacted their sense of self-efficacy and health outcome, which was also noted in other studies (Keeton et al., 2008; McCarthy & McMahon, 2008). For example, Amy's unsuccessful attempts at accessing care and community resources, at various times in her experience, and the lack of information about her diagnosis of bipolar disorder and the implications of psychotropic treatment and the risk of relapse impacted her self-efficacy and ongoing mental health problems (Corrigan & Wassell, 2008). She felt powerless, trapped and isolated, sentiments also expressed by Elyse.

According to Brown (2006), power consists of awareness, access to choice and the ability to affect change. Some participants demonstrated a sense of being in control of and being proactively engaged in managing their own mental health problems by choosing to forgo and/or discontinue psychotropic medication in favour of alternative and more holistic approaches (yoga, diet, stress management, becoming self informed, and choosing to develop adaptive cognitive/behaviours strategies to manage mood lability), which facilitated positive health outcomes. This was despite the lack of treatment engagement and options. This demonstrated a sense of self-efficacy and shame resilience that related to feelings of empowerment, the freedom to choose and explore options, and the importance of information, education and knowledge to enhance women's sense of being in control and empowered (Brown, 2006).

***Level of self disclosure.*** All of the women in this study used selective disclosure as a means of being in control of and/or avoid self stigma/shame. For some participants, as seen in other research, selective disclosure was helpful in certain situations and with certain people as it provided a sense of control, perceived support, and buffered their sense of self; further, selective disclosure decreased their self stigma as it helped to normalize their experience facilitating their sense of self-efficacy (Bos et al., 2009; Corrigan & Wassell, 2008; Edwards & Timmons, 2005; Vauth et al., 2007). However, for some women selectively disclosing greatly impeded their access to appropriate mental health care, their level of treatment engagement, and their social interactions, which further impeded their sense of self-efficacy and health outcome.

The fear of disclosure due to self stigma/shame and the underlying fear of being labeled and judged was a significant factor in women's experience of maternal mental illness and seeking help, as in other studies (Corrigan & Wassell, 2008; Dennis & Chung-Lee, 2006; Edwards & Timmons, 2005; Einarson, 2009a; Goffman, 1963; Marcus, 2009; McCarthy & McMahon, 2008). This was evident in the present study as each participant would gauge, or selectively disclose how or to whom, when and how much, they would share personal information (about their mental illness and/or infertility issues), in order to moderate or escape the effects of self stigma/shame. Some of the participants spoke of an element of secrecy and social taboo associated with maternal mental illness, and revealed feelings of shame, blame and guilt when admitting to withholding information and/or minimizing the severity of their mental and emotional distress (Corrigan & Wassell, 2008). Some acknowledged their efforts to hide their mental illness - "passing" as normal or putting on another "persona" - to avoid being stigmatized, judged, and/or discriminated against and to be seen as incompetent (Corrigan et al., 2009). Some avoided situations/people to maintain secrecy, and others would selectively disclose

when they perceived stigmatization from family, friends, and others. Similar to the research, some of the women's fear of disclosure was intensified by unsolicited comments and jokes, which fostered feelings of isolation and withdrawal from social interactions, which further impacted their emotional status, treatment engagement and health outcome (Slade et al., 2007). Findings revealed the participants who seemed to experience more shame/self stigma were more likely to fear disclosure and discovery which diminished their sense of empowerment and sense of self-efficacy.

***Coping strategies.*** According to Gourounti et al. (2013), coping refers to “a person's cognitive and behavioral efforts to master, reduce, or tolerate the internal and/or external demands that are created by the stressful transaction, which serves the function of regulating stressful emotions and managing the problem that is causing the distress” (p. 354). The effectiveness of women's coping strategies emerged as another aspect that influenced women's level of self-efficacy and sense of being in control, which could be conceptualized on a shame resilience continuum.

Several coping strategies that the participants used to moderate and/or regulate their experience of mental illness and self stigma/shame could be interpreted as representing a range of shame resilience. These behaviours were intricately linked to their sense of self-efficacy and included maladaptive behaviors such as self harm, denial, withdrawal, avoidance, resistance, disengagement, overwork, limited self-care, and why-try responses. Some of these behaviours are noted in the stigma research (Corrigan et al., 2009) and reflect a low sense of self-efficacy/shame resilience and a high level of self stigma/shame. These maladaptive behaviours related to Amy and Elyse's health outcome, ongoing mental health problems and their feelings of being powerless, trapped and isolated. As in this study, researchers have found that maladaptive

coping strategies are linked to the risk/exacerbation of maternal mental illness (Gourounti et al., 2013) and maintenance of high levels of perceived stigma and a decreased sense of empowerment (Vauth et al., 2007).

The participants' more adaptive coping strategies that reflected a low or lack of self stigma and higher sense of self-efficacy included ambivalence, positive attitude, shared experience, conscious choice and proactive engagement (healthy lifestyle, learning new cognitive/behavioural skills, and seeking and gaining knowledge and understanding), also identified in Brown (2006). These behaviours related to feelings of empowerment, of being in control, of being free from self stigma/shame, and of being supported/connected (Pinto-Foltz & Logsdon, 2008; Restall & Strutt, 2008; Wardrop & Popadiuk, 2013) which played a significant role in women's (Skye, Tina, Sue and Gabby) treatment engagement, satisfaction and positive health outcomes.

***Ambivalence as a protective factor.*** An interesting finding revealed that ambivalence seemed to play a role in the participants' experience of self stigma and was a protective factor in their experience of maternal mental illness: "Ambivalence is the existing of two or more opposite or conflicting feelings, values or meanings" (Leichtentritt et al., 2005, p. 21). Several authors have also noted a shared experience of maternal ambivalence in women's experience of maternal mental illness (Arendell, 2000; Leichtentritt et al., 2005; McKillop, 2009). According to Weigert (1991), ambivalence is often experienced or perceived as an undesirable state, seen as a sign of weakness or indecision. However, similar to this study's findings, some researchers have suggested that a sense of ambivalence can be perceived as having the confidence to recognize both sides of an issue, having the awareness of alternatives and the possibility of positive outcomes which functions as a calming influence (Leichtentritt et al., 2005; Weigert, 1991). This



study, like others, found that for women with high-risk pregnancies (e.g., Skye, Tina, Gabby, Sue), ambivalence had a positive effect “as it is a dialectical concept that can have a calming influence on the women, because the possibility of positive outcomes exists” (Leichtentritt et al., 2005, p. 21).

The shared experience and shared meaning of ambivalence in participants’ experience of maternal mental illness revolved around issues, such as the myth of motherhood versus the reality, treatment engagement and treatment satisfaction, biomedical versus bio-psycho-social approaches, and the level of support. As in recent studies (McKillop, 2009; Wardrop & Popadiuk, 2013), participants spoke of the disconnection between the myth of joyful motherhood (always being happy vs. feelings of anger and frustration), intensive/perfect mothering and the realities of the challenges of parenting. Some of the women identified and internalized these social norms and scripts, to a greater or lesser degree, which became a gauge by which they judged themselves, greatly impacting their experience of mental illness, shame, and health outcome (Brown, 2006). While other women were more ambivalent about the realities of being a mother, needing help, and having a maternal mental illness which seemed to be linked to a sense of self-efficacy/shame resilience and low self stigma/shame.

Some participants were ambivalent about their treatment experience of using psychotropic medication versus the lack of treatment options and/or information and education. Further, the only participant who attended a support group for postpartum depression described her experience as being both positive and negative. Wardrop and Popadiuk (2013) noted women with maternal mental illness also benefitted from have support from other mothers, which helped normalize their experience. On the one hand, she felt supported when the group helped her realize that other women had similar experiences, but on the other hand, she felt some of the

women were judgmental. For some participants (Skye, Tina, Gabby) needing medication or being on medication did not have a significant impact on their sense of self nor their treatment engagement, but rather they had a sense of ambivalence about medication. On one hand, the medication provided relief from distressing symptoms and allowed them to cope with their mental illness; while on the other hand, they worried about the cost, the safety of the medication and/or being tied to the health care system.

The participants were able to make sense of their experience of stigmatization when accessing mental health care in a manner that suggested it contributed, either positively or negatively, to their experience. For a few women (Skye, Tina, Gabby), a sense of ambivalence seemed to be connected to a lack of shame/self stigma and an enhanced sense of self-efficacy. Interestingly, these participants also had a history of anxiety which was successfully treated with medication and/or a family history of mental illness. This familiarity may have also played a role in facilitating a sense of ambivalence that seemed to reflect lower self stigma and shame, the level of treatment engagement and self-efficacy. Other researchers (Corrigan & Watson, 2007; Tognazzini et al., 2008) have also identified knowledge and experience through contact and familiarity with people with mental illness reduced stigma; however, the research is largely on the training and education of health care providers. The findings of this study revealed that for some participants their familiarity and contact with mental illness seemed to facilitate a sense of ambivalence which was connected to less self stigma/shame and a more positive sense of self-efficacy/shame resilience.

***Perceived level of support and connection.*** In this study, the level of perceived support and sense of connection influenced women's experience and outcome of maternal mental illness as other researchers have identified (Gold, 2002; Kalra & Einarson, 2006). For the majority of

the women, the perceived level of support and a sense of connection (Bos et al., 2009; Restall & Strutt, 2008; Wardrop & Popadiuk, 2013) with their spouse, family, close friends, other mothers, and especially in terms of their relationship with their family physician, were identified as factors in seeking help, accessing care, level of self-efficacy and feelings of being in control and empowered, and treatment experience and health outcome. Evident in the findings, some women found connection, shared experiences and mutual support through selectively disclosing their feelings and concerns with others which helped normalize their own experience, also noted by other studies (Bos et al., 2009; Restall & Strutt, 2008; Wardrop & Popadiuk, 2013). However, for Amy, the lack of perceived support and sense of connection was clearly a barrier in her experience of maternal mental illness; not having family support due to proximity and their religious beliefs, a lack of community and social support, and a lack of connection with friends and co-workers were significant contributors to her ongoing mental health problems.

The perceived level of support and sense of connection in participants' interactions with health care professionals and accessing mental health care were related to the importance of their relationship with their family physician and the level of empathy, personal experiences of stigmatization, amount and/or quality of information, education, feedback, resources and services about the bio-psycho-social implications of maternal mental illness, the process of assessment/diagnosis and the lack of treatment options and support within a biomedical model. These had an impact on women's experiences of shame, their sense of self-efficacy and their feeling of empowerment and was a factor in women's experience of mental illness and their treatment engagement and satisfaction, and health outcome.

## **Implications for Practice**

Several implications for clinical and counselling practice emerged from this study, which are important to consider when providing care to women with maternal mental illness. In order to fully support women with mental health problems and their families, health care providers must go beyond a biomedical lens to identify, address, and consider not only biological risk factors/implications, but also psycho-socio-cultural factors/implications, such as lack of support, the method of conception, and self stigma. Health care providers need to be aware and develop a deeper understanding of the role stigma plays in women's experience of mental illness and treatment experience (Bos et al., 2009; Corrigan & Wassell, 2008; Restall & Strutt, 2008), but more specifically how stigma becomes a shame experience (Brown, 2006). It is important to include women, spouses and families in the assessment, management and education of maternal mental illness and to provide them with information, education, resources, access and support, in addition to treatment options (Marcus , 2009; McCarthy & McMahon, 2008). Health care providers need more training and educational opportunities to enhance their knowledge, comfort level, understanding, awareness, and sensitivity to the bio-psycho-social needs of childbearing women' and their families (Corrigan & Wassell, 2008; Scultze, 2007, Thornicroft et al., 2007; Tognazzini et al., 2008). There is a need for the therapeutic approach to go beyond the biomedical tradition to promote more transparency, sensitivity and self-reflexivity on the part of health care providers and mental health care programs to minimize the impact of stigmatization on women's experience of accessing care, treatment satisfaction and health outcome (Brown, 2006; Schulze, 2007; Thornicroft et al., 2007). Further, an empowerment approach to providing care, which identifies the client as the expert, can guide mental health care and support

provisions which emphasizes health, abilities, personal control, and effective change and resources (Restall & Strutt, 2008).

According to Brown's SRT (2006),

The goals for practitioners working with women on shame issues should be to help clients identify personal vulnerabilities, increase critical awareness of their shame web, develop mutually empathic relationships that allow them to reach out to others, and learn to speak shame. Given the focus on raising critical awareness and education, psycho-educational group work or a combination of individual work and psycho-educational group work should be considered (p. 51).

Moreover, implications for practice should focus on decreasing women's experience of stigmatization and shame and increase their sense of being in control and empowered by facilitating their resilience and sense of self-efficacy. In order to do this, shame needs to be addressed directly in therapeutic practice and by incorporating a psycho-educational stance to inform women and their families of the bio-psycho-social factors and implications of maternal mental illness and to empower them with information, education, increased awareness and choice (Brown, 2006; Restall & Strutt, 2008). Health care providers can foster shame resilience through their support and empathic connection and by addressing women's feelings of shame, powerless, trapped and isolated. Women should be empowered and encouraged to develop adaptive coping strategies (sense of ambivalence, for example) and to increase their level of support and connection through shared experiences and accessing community resources (Brown, 2006; Restall & Strutt, 2008; Wardrop & Popadiuk, 2013). By facilitating women's awareness, access to choice, freedom to explore options and the ability of affect change in regards to their

own mental health, health care providers can enhance women's sense of empowerment and positive health outcomes (Brown, 2006; Restall & Strutt, 2008; Wardrop & Popadiuk, 2013).

### **Study's Limitations and Strengths**

Key limitations of the study include a lack of diversity among participants; the one-time collection of data; and the long period of time that lapsed between data collection and its analysis. The women in this study were all Canadian-born, white, middle-class women; and five of the six women were in their 30s. The applicability of these findings to other groups of women is unknown. This was also a group of women who chose to volunteer and there may be characteristics and motivations that distinguished them from those who chose not to volunteer. The use of only one interview limited opportunities for further reflections, which might have increased the richness of understanding and allowed an opportunity to delve more deeply into particular findings. Last, the analysis and write-up of findings took place over approximately four years.

The value of this study was that, although limited in sample size, it provided a unique exploration of the bio-psycho-social dimensions of women's experience of maternal mental illness, the role of stigma, seeking help, and accessing mental health care and exploring the interconnections and relationships between them, from the perspective of women who experienced maternal mental health illness and sought care. Researchers have argued that qualitative interpretive inquiry is validated, not by numbers of participants, but by the completeness of the examination of the topic and the depth to which the interpretation extends our understanding (Kearney, 2001; Sandelowski, 1994; Thorne, 2008; Wardrop & Popadiuk, 2013). The available research on maternal mental illness, the impact of stigma, and accessing mental health care is predominately quantitative emphasizing a biomedical approach focusing on

psycho-pharmaceutical interventions. This study goes beyond this by providing a detailed description and analysis of six women's lived experience, bringing to light the interconnections between psycho-social factors/implications, socio-cultural context and personal experiences of stigmatization. Further, the interviews provided the six women with an opportunity to share their perceptions of accessing mental health care services, and to offer recommendations and advice for improving women's care satisfaction and health outcomes.

The findings add to the current literature in the following ways: a new conceptualization of self stigma of maternal mental illness and shame resilience using Brown's SRT; identifying ambivalence and familiarity as potential protective psycho-social factors that enhance shame resilience; and highlighting a shared experience of infertility and the process of IVF as a significant psycho-social-cultural factor in women's experience of maternal mental illness and shame.

The relevance of the study findings from a clinical perspective is that it underscores the importance of identifying, addressing, and being sensitive to women's experience of stigmatization and feelings of shame when providing care and effective treatment options and support to enhance positive health outcomes, especially based on an empowerment and relational approach (Brown, 2006; Restall & Strutt, 2008). Hopefully the findings provide health care providers and other women with a deeper understanding of the importance of considering the psycho-socio-cultural context, within which pregnancy and motherhood takes place.

As suggested by McCormick and Bunting (2002), a feminist lens brought several elements to the study that I consider a strength. The study sought to validate and value women's subjective experiences, perceptions, ideas, and needs in regards to their experience of maternal

mental illness, stigma and their experience accessing care. The benefit of using a feminist lens in this qualitative health inquiry was to validate and facilitate the exploration of women's experience of maternal mental illness and stigma, as gendered issue embedded within and influenced by the socio-cultural discourses of reproduction, motherhood and mothering, traditionally informed by scientific and biomedical discourses (Koniak-Griffin et al., 2006). Feminist researchers have illuminated the importance of using a feminist social constructionist approach when exploring and seeking to better understand women's experiences of maternal mental illness embedded and influenced by the socio-cultural discourses of motherhood and mothering (Arendell, 2000; Choi et al., 2005; Cosgrove, 2000; Mauthner, 1998). "This paradigm affords a means for looking at, and taking seriously, interactions, interpretive processes, social context, and importantly, relationships" (Arendell, 2000, p. 1202).

According to Sandelowski and Barroso (2003), descriptions "always depend on the perceptions, inclinations, sensitivities and sensibilities of the describer" (p. 913). A feminist approach allowed the emphasis to be on women's subjectivity, the context of their experiences and the meaning made from those experiences constructed through historical and cultural influences and social practices, processes, and institutions, as well as through interactions and encounters with their family members, others and most importantly, health care professionals. It was through a feminist lens that the bio-psycho-social dimensions and interconnections between stigma and shame and self-efficacy and shame resilience emerged and re-conceptualized using Brown's SRT (2006). A feminist stance confirmed the need for reflexivity on all levels, that is to say, the importance for researchers/clinicians and health care providers to engage in ongoing self-questioning of assumptions and biases and the impact these have on women's experience of mental illness and shame (McCormick & Bunting, 2002). The emphasis should be on



understanding, identifying, addressing, and being sensitive to the impact of self stigma and shame that may play a role in women's experience of mental illness, willingness to seek help, accessing mental health care services, treatment engagement, and health outcome (Brown, 2006).

The feminist framework revealed and validated the importance of relationships in women's experiences and interactions with family members, others and their health care providers (Arendell, 2000; Cosgrove, 2000). But most importantly, the findings revealed the importance of enhancing and facilitating women's strengths, self-efficacy and feelings of connection, empathy, and empowerment which reflects other research (Brown, 2006; Corrigan et al., 2009; Restall & Strutt, 2008; Wardrop & Popadiuk, 2013).

### **Future Research**

Findings of the study highlighted several areas of interest and the need for more qualitative research investigating the women's experience of maternal mental illness and stigma. There is need for further research on women's experience of infertility and the process of IVF as risk factors for developing maternal mental illness and an aspect of women's experience of self stigma and shame, and the implications of biomedical and medicalized processes of reproduction on women's sense of self and mental health. Study findings were based on a homogenous group of women, hence the importance of exploring the experiences of mental illness and self stigma among women of other ethnic groups, socio-economic classes, and other age groups which could bring greater understanding of these experiences and intersections with culture.

The study findings suggested the importance of ambivalence as a potential protective factor in women's experience of maternal mental illness and shame/self stigma. Further, ambivalence seemed to be linked to shame resilience which warrants further exploration. Using

Brown's SRT (2006) to conceptualize self stigma as shame, and self-efficacy as shame resilience and empowerment, support the use of a bio-psycho-social model as a therapeutic approach to provide mental health care for childbearing women and their families. This would be an interesting area of research which could go beyond the underlying biomedical approach of mental health care services typically provided to women with maternal mental health problems.

Participants shared experiences of maternal mental illness, stigma and accessing mental health care services revealed the biomedical context within which assessment, treatment, support, crisis intervention, and follow-up are experienced. Current findings suggest that the adoption of a bio-psycho-social approach could be more focused and fully integrated into all aspects of service provision, including the therapeutic relationship. This is especially relevant in terms of addressing and decreasing experiences of stigmatization and shame when dealing with maternal mental illness. The bio-psycho-social perspective (such as Brown's SRT) can provide a framework for providing mental health care services and enhancing the process of clinical assessment, screening, diagnosis, treatment options and education, including psycho-social risk factors, and identifying the impact of socio-cultural context and stigmatization to address women's experience of maternal mental illness.

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